SINGING YOU AWAY: AN EXAMINATION OF COMMUNITY AND SELF-DISCOVERY THROUGH ILLNESS NARRATIVE

SHANNON E. NORTH

Singing You Away:

An Examination of Community and Self-Discovery through Illness Narrative

Shannon E. North

Submitted to the faculty of the University Graduate School in partial fulfillment of the requirements for the degree Master of Arts in English in the College of Liberal Arts and Sciences

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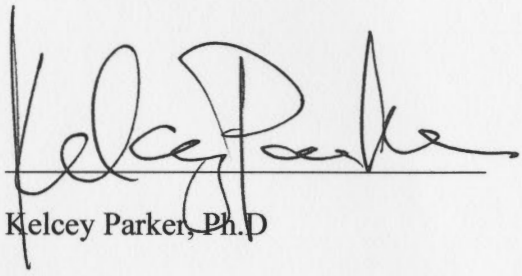
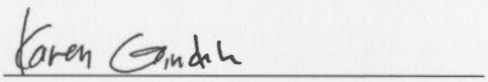
M.A. Committee

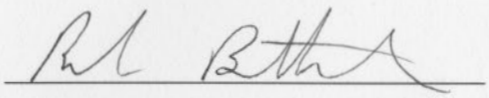


Kelcey Parker, Ph.D

Director



Karen Gindele, PhD.



Rebecca Brittenham, Ph.D

August 17, 2011

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Dedication

The writing of this personal narrative is dedicated first to my children, C.S.N., and M.S.N., for without whom I would never know I had any own importance in this world, and also to my good friend, P.J.M., "Calidore." Nary has a day gone by that you are not in my thoughts; your songs are on my stereo so often, my kids sing along with them. See you in that other life.

Acknowledgements

I would like to extend my greatest appreciation to my committee, Drs. Rebecca Brittenham, Karen Gindele, and Kelcey Parker. Thanks to all of you for your help and support during the writing of this project. It was a difficult piece to execute and never would have come to fruition without the support of my committee.

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As well, I extend my gratitude to the entire English Departments at Indiana University at South Bend, particularly Joe Chaney, David Dodd Lee, Margaret Scanlan, and Jake Mattox for nurturing me as a student and as a writer from my early days as an undergraduate student to these final months of the writing of my Master's Thesis.

Finally, my husband, Gregg, has been patient and supportive of me through this sometimes tedious journey toward my degree, supporting our family and my education without complaint. Thank you.

SINGING YOU AWAY

A PERSONAL NARRATIVE ABOUT LOVE, LIFE, AND DISEASE

2007

Your heart is true, you're a pal and a confidante

Outbox:

Wanderlost > Calidore:

November 25, 2007

I didn't do my Vest last night. My dad was here and I am still kind of embarrassed about the contraption. Later, I lay in bed, awake and feeling guilty. I imagined the bugs reclaiming their space. This disease is going to kill me. For how many years was I sure that I would be different? I was not like "them." I was lucky. How long does luck last?

I feel this meshing of my identity with CF rather than a separation of the two: Shannon has CF. But I am still afraid of that admission. I am afraid to see the fear in my parents' eyes the first time I have to go to the hospital, the pity from my husband, uncertainty from my children. I don't want to see the naked worry. My pride is not ready for this yet. Foolish girl.

Inbox:

Calidore > Wanderlost:

November 26, 2007

Don't you think runaway pride is often a compensation for some dark part of ourselves we're afraid to own up to? That's the self-loathing, I think. If we loved our

entire selves, wouldn't we embrace all parts of them? Why do we conceal this segment of our genome but not that? It's like the girl who wears too much makeup.

December 2009

I'm so lonely, I wish I was the moon tonight

I've traveled through the industrial smog of northwestern Indiana over the Skyway and into Chicago dozens of times. This December morning, I felt as if I was being held together by loosely strung chicken wire and the billowy plumes of noxious gas from the Gary factories irritated my already tightened chest. The morning was crisp sunshine, cars whirring with ease across the freeway, but I drove feeling as if a cast iron skillet had been wedged into my sternum.

The jagged skyscrapers and mirrored high rises of the Chicago skyline unfolded into view just as Neko Case's song "I Wish I was the Moon Tonight" played on the iPod rotation. Don once told me he'd had Neko Case's phone number. I didn't doubt it. Don was just the kind of man to have dated a country music goddess.

Don once wore a bear skin trench coat and drank enough whiskey to jelly a liver; he snorted cocaine with Swiss girls and had sex with his nurse in the hospital parking lot. Don was a Merton fan and spent time at Gethsemane Abbey. He visited Flannery O'Connor's childhood home and Keats' grave. Don won a Michener fellowship as an MFA student at Iowa. He was a man of words, stringing them together so fluidly I'd become drunk just from reading. The first time I met Don, he wore a green army jacket in the July heat, the collar adorned with Obama pins, his brown hair shaggy, just resting

atop his collar. Don was the man who told me, "But really I gave up the Dickel for the Dharma, as one must do eventually."

My car vibrated over the metal grid of the Skyway and as I merged onto the Dan Ryan, my heart ached with the twang of a sad country tune of lost love, empty bottles, and all that might have been.

1989

Never trust a big butt and a smile, that girl is poison

1989 was the year the Berlin wall came down. It was the year of my first kiss (Ken M.) and my first concert (R.E.M.) and not the year of my first period (1990). I was twelve in 1989, growing out a failed home perm that my mother attempted in our kitchen on Adams Street. Adams Street was on the Northwest side of South Bend, bordered by the grand old farm houses on Portage Road to the East and the harsher vacant and weeded lots of Elwood Road to the south. The houses dated back to the forties when the northwest side of South Bend was a vibrant and booming area, home to Drewery's brewery and the first Martin's Supermarket. We lived in the seventeen hundred block of Adams Street which was still an average middle-class neighborhood, but just a few blocks to the west or to the south the neighborhoods became weedier, rustier, tighter. I had my own blue bedroom in our house with a tiny closet that my mother assured me must have been made for a small girl like myself. My brother lived with our father about two miles away in a historic house on Riverside Drive. It was the house my parents bought after returning from living in Jamaica where my father worked on his dissertation

as an anthropology student studying at the University of the West Indies, the writing of which he would not finish for nearly ten years after executing the research. In 1989 my parents had been divorced for five years.

The summer of 1989 was the summer between elementary school and middle school. I secretly listened to Bob Marley and Sinead O'Connor. Michael Jackson was no longer cool. I had no breasts yet, but wore a bra anyway. That summer my friends and I snuck out of the house in our nightgowns, crossed the St. Joe River at the wood-planked railroad-track bridge by the Lock Joint Tube factory, and drank my mother's peppermint schnapps, passing the bottle between us and wiping at our mouths like we'd seen in the movies.

That was the same summer that my father and step-mother hired a nanny to take care of my siblings and me, mostly to drive us to swim practice and the community pool. Melody was tall and blonde, she had boobs. She had pointy hip bones and when she lay on her back, her bikini bottom stretched taut from hip to hip leaving a gap where the fabric hovered over her tanned, flat belly. She had an inny belly button while I had an outty. I loved and hated her. I lay by her side all summer at the pool relishing the attention that all the male lifeguards lavished on us. I knew they were looking at her, but I pretended they were looking at me. I daydreamed about kissing them. I was twelve but looked eight, inside I felt seventeen. I imagined myself as a girl in a Poison video.

1989 was also the year that a geneticist named Lap-Chee Tsui lifted his dry, curled fingers toward the halogen bulbs of his stark, white laboratory and shouted, "Eureka!" when he discovered the gene that causes the genetic disease Cystic Fibrosis. It was the year that hope was given to the thousands of children and young adults living

with that disease who had a life expectancy of only eighteen years. This finding gave shape to the dream that the elusive cure, always "ten years away," really was on the horizon. And, because I was one of those children, it was the year that my mother called me at my friend Ellen's house crying, "They found it! They found the gene that causes CF!" I pretended not to understand her excitement. I was angry with her for calling. Even then I knew that a cure was just a pipe dream. I no longer believed in anything hopeful related to CF, only in what ways I could obliterate it from my life. My mother calling and crying in joy was not one of those ways. I snarled, "Big deal," and popped a stolen Virginia Slim into my lipsticked twelve-year-old mouth as I slammed the phone into the receiver without a goodbye.

My memory of life with Cystic Fibrosis is hazy up until that point. There are certain things that stick out from my younger years: being filmed on the news as a preschooler in a segment about the disease; hating my pediatrician who was also my CF doctor; having daily percussive chest physiotherapy; but up until age twelve, these things were mostly just an accepted part of my life. It was the previous August that the change began to ferment. Before the peppermint schnapps and Lap-Chee Tsui's unprecedented discovery, I had just been an average, prepubescent Cystic Fibrosis patient. That August, as every other, I reluctantly followed my mother into my school to meet my new teacher for the year. Since preschool my mother had dutifully appeared before that year's teacher to present the Cystic Fibrosis Foundation's pamphlet "A Child in Your Class has Cystic Fibrosis." She had been told this was the best protocol by the social worker at the CF clinic and she did it annually without fail. The pamphlet explained what CF was and about my coughing and my medication. I had heard the spiel with every new friend and

every new teacher, but that August I noticed something different. There was something off about the way my new teacher, Mrs. Buyers, looked at me. It wasn't disdain for my crimped hair and Guns-n-Roses t-shirt, as my mother had griped would probably happen when we'd left the house; it was something grayer, sadder. As we left, Mrs. Buyers' smile was less vibrant, more like one looks as she steps away from a sickly puppy.

That night, I took a copy of the "A Child in Your Class has Cystic Fibrosis" pamphlet from its niche between a pack of menthol cigarettes and a wallet in my mother's purse and snuck it into my blue bedroom.

"CF is a genetic disease. It is the most common life-shortening disease among Caucasians; people with CF are living longer than ever, often into adulthood (age 18 and older). Thick sticky mucus builds up in the lungs leading to recurrent lung infections. Malabsorption leads to poor growth, stomach cramping, and frequent, loose, foul smelling stools. Other complications such as liver problems, diabetes, and reproductive system effects can occur."

Seeing my disease in print, knowing this was why my new teacher had looked sad, angered me. Who wrote this? They were liars! I was none of these things. I was pretty, smart - how could I assimilate words like sticky mucous, foul stools with that image? It wasn't those things; I was those things. I had to admit that I had all the issues listed. I'd accepted the way the disease had settled like smog over our house, the orange and white pill jars that littered the counter, the percussion therapy - lying over my parents' laps as they clapped on my back, chest and sides to loosen the sticky phlegm from my lungs – it had been the only way of life I'd known. At that point, I was already irritated with my doctors who said I should not have a cat, who said I might start my

period later than my peers, with the constant flu shots and breathing tests, the social workers who meant well, but who spoke in such a maple sugar sweetness that I simply wanted to bite them. Still, all of that had been segmented, a separate yet accepted part of my life. Even at that point, I had separated the CF part of my life into its own place separate from the rest of my life, but I'd never really thought about what it all meant.

I'd never been ignorant about my disease, but I had been blinded to the reaction that it elicited from others. The look in Mrs. Buyers' eyes combined with the pamphlet I held in my hands caused a reaction in me so fierce I almost shook. It felt as if tiny explosions were vibrating my young body as my mind reeled over the past twelve years. I was smaller than the other kids; I had to take pills when I ate. All of these things began to anger me. It wasn't fair. And death by eighteen? That was only six years away! All I really knew of death was that I'd had a goldfish that died when I was a child and when I'd dug the carcass back up weeks later I found a rotting gunky mess of bones and flesh. Suddenly I felt acutely aware of how others reacted to the knowledge of my disease, the pity they exuded, the assumptions they made, the limitations they expected me to have. They thought I was going to be dead soon, that my life was crippled and suffering. It was all here in black print, the road map of my life with CF. The story was set and the life narrative was prewritten for me simply by being born with the disease. It wasn't until I read the pamphlet for myself in my blue bedroom that I became acutely aware that the disease was really a defining factor in my life. *I* was the child in the class with Cystic Fibrosis.

I felt the hope of a normal life being sucked away from me. I pushed the pamphlet with the pretty child on the front away from me and dissolved into some kind of twelve-

year-old mental whirlwind. In that vacuum I visualized talons growing from my hands, rays of red sprouting from my eyes. CF would not take me. I would not be thick and sticky and foul. It wasn't a war I was waging, it was an absolute obliteration of all expectations. It would be the disintegration of every word ever written about CF in relation to me. I would not be what they said. I would need nothing. CF was an earwig and I was a shoe. If I'd idolized the rock goddess heroines of my MTV youth before, now I would become one. I would be shiny, golden, cherry red lips, a girl who was beautiful and desirable and wild and who in her three-minute moments of MTV glory would never cough or shit or be anything other than perfect.

I became, at that moment, a twelve-year-old girl with CF who didn't have CF.

1947

Down with disease and the jungles in my mind

In a case study of adults with CF awaiting transplant, anthropologist Ronald Maynard poses this question:

> What if your body reordered yourself narrative? What if you were born with a disease and your parents were asked if they would rather leave you at the hospital to die? And if they took you home and you did not die, what if they were subsequently told you would not live to be a teenager? And then, not to adulthood? What if, as a young adult, you were told you would not live beyond your early thirties? What if your life was a living testimony to failed prognostication, limited knowledge, and the overestimation of risks, a life

> comingled and often confused with the mortality of similarly diseased individuals? In short, what if given your disease, you are a biological success? (226).

This idea of failed prognostication defined my rebellion. Despite knowing that CF was a fatal illness, nothing in my experience or belief system, none of what I read or heard about my disease seemed to apply to me. Part of my anger at my disease was the constant expectations placed on my life. I didn't feel like I was dying. I could run and play just as well as the other children, yet everyone wanted to give me these special considerations. I didn't want or need anything special. The best thing anyone could do for me was to leave me alone.

The few CF-related aspects of my life that I could not escape, I became an expert at hiding. I learned how to take my digestive enzymes in a way that no one ever noticed. I'd slip them from my pocket and hold them in my hand until the person I was with looked away. Immediately I'd pop them in my mouth and swallow. I learned how to stifle a cough with a laugh. I could hold in gas or a bowel movement for hours. I rarely became sick with pulmonary infections, though CF was easy to push off as asthma, a cold, or bronchitis. The better I got at hiding the disease, the more schooled I became in the game of CF denial. It wasn't hard. Denial ran deeply in my family. I wasn't the first person with CF in our tribe, though often the disease was the proverbial elephant in the room. My maternal uncle also had CF, and before him an aunt who'd died.

The story of CF is one of a mutated set of genes passed down over generations. One mutated gene passed to some Irish woman here on my mother's side, one passed to some Flemish man there on my father's side, who passed it on to his daughter and the

daughter to her son and so on, until both my parents, unknowingly mutated, met one another and those two misfit genes coalesced into a the helix chain of proteins that changed me from a clump of cells resembling a lima bean to a fishy alien fetus to a very sickly baby. It takes one mutated gene from a mother and one mutated gene from a father to give each blossoming fetus a 25% chance of having a pair of mutant genes herself. An unlucky roll of the dice for that fetus, as each progeny of a set of mutant carriers has a 25% chance of having the disease, a 50% chance of simply carrying the gene (and then possibly passing it down to their own child), and a 25% chance of being scott-free mutant gene-less. I was the unlucky 25 percenter who inherited both genes and therefore Cystic Fibrosis. So was my uncle, and so was my grandparents' first baby, Christine.

My grandfather, a farmer's kid and product of the Great Depression, returned from the Pacific Rim and used his GI Bill to graduate from the University of Arizona. My grandmother, the daughter of a dentist and attendee of Grinnell University in Iowa, married my grandfather in August of 1947. Close to a year later, my grandmother birthed their first child, Christine.

"Chris started coughing so the nurses didn't want to feed her either, so our doctor would sometimes leave his office and go down and feed her. Now that's a wonderful doctor," recalls my grandmother as she retold Christine's story. "He said he went to the hospital library every night and studied and studied and studied and tried to find out what she had and he said, 'I think fibrocystic disease is what she has.'

"Chris turned real dark, and Dad just didn't want me to see her like that. Then that was just it. She couldn't eat. She couldn't do anything and she died on Thanksgiving Day." My grandmother spent only the first four days after the birth of her first-born baby

with the child. Once Chris became sick, my grandmother was sent home, alone. After four days, she neither held nor saw her daughter again. There are no photographs.

"Dr. Guinta told Dad and I, 'Go ahead and have your family. There are only about 16 cases of this in the world and there's no problem. Have your family.' So we did. Then they came back years later and said it's two out of four when they really decided what it was...."

My grandparents went on to have three more children: my mother Patty and my uncles Jim and John. When Jim was five it was discovered that he too had Cystic Fibrosis. In my uncle's recollection, he never knew he had the disease until his third grade teacher chided him for not knowing what CF was and made him read the definition aloud to his class from an encyclopedia. My mother disputes this as truth, but I don't think that there can be any question that denial ran deep in our family. We just didn't talk about the disease. My parents ensured I did the minimal required maintenance care: digestive enzymes, bronchodilators, vitamins, antibiotics, and percussive chest therapy, but we rarely acknowledged why I did these things. I don't think my parents purposefully set out to make my disease a secret. It many ways it wasn't. They told their friends and my friends' parents. They told my teachers, and any other person who had a need to know the information, without much hesitation. It was just that they didn't talk to me about it. Medically, yes. I understood why I had to take my pills, why I had to do percussive therapy, but these things were just part of our daily routine. They didn't talk to me about how I felt having to take pills or if I was embarrassed when I coughed or my feelings about the disease. I assume this stemmed from fear. They were afraid that I would not live a normal life, that I would be afraid of my disease, that I would die. They

were certainly afraid to talk to me about death. This in turn made me uncomfortable talking about my disease; I became ashamed and embarrassed and so denial steeped, and in the dregs of denial brewed a deep sense of loneliness. There was no one I could talk to about how I felt, so I just wouldn't talk about it at all. Certainly my clinic tried. They had social workers on staff to help patients deal with life with a chronic illness, but I saw them as simply another cog in the irritating CF wheel. As well, my mother was a social worker and I can't help but wonder if maybe that kind of care was simply deferred to as something she would handle at home herself.

When I denied my disease as a part of myself, something went awry with my sense of worth, though I didn't realize that until many years later, after I met Don.

1992

Sexy Sadie however big you think you are

As far back as my memory stretches it seems like men always wanted me to sit on their laps, pull up my shirt, whisper in their ears. Not men that I knew, strangers, mostly. There is no incest or molestation in my story, but there is a pervasive sadness associated with my dealing with men. I let myself be exploited while thinking the whole time that I was the one doing the manipulating. It didn't start this way though. Besides my father, I was intimidated by most other men. I was petrified of the two male teachers that worked in my elementary school. Mr. Benson, a short, red-headed fifth-grade teacher, would often pick me up and carry me down in the hallway if I couldn't escape him soon enough. Dread enveloped me one morning after I heard my teacher, Mrs. Thomas, report to

another teacher, "I think Mr. Benson has a crush on Shannon." This was attention I did not want. It made me feel bad, like I'd done something wrong.

J.T. the lifeguard and Tim the swim coach (once my parents could no longer wrestle me down to perform percussive therapy, they put me on a swim team as a means to help keep my lungs clear) both tried to get me to sit on their laps, and while Tim, who called me "Shanooon," might have had innocent intentions, J.T. I was never sure did. Something in his eyes told me otherwise, though it wouldn't be for many years that I would recognize and even strive to attain that same kind of lascivious look. Instead, I would hide in the women's locker room until my father was finished in the men's and could meet me in the hallway where the lifeguard's office was stationed. I never wanted to be alone with J.T. and his grabbing hands.

At twelve I had the same insecurities as every other twelve-year-old girl. I wanted to be popular, I hated my braces, I wished I had boobs. I read *Are you There God, It's Me Margaret* and actually did the "we must, we must, increase our bust" exercises. But by fourteen, something magical happened. I discovered my sexuality, and in that a new way to say fuck you to CF. I imagined CF girls as scrawny, sickly, ugly. I wanted to be the antithesis of that. Associating myself with CF made me afraid, so I lit a fire to extinguish all traces of the disease. I wore clothes that accented my figure. Though I was tiny, I was shapely, and I started to understand that the "lovely girl," people remarked on as a child could now be considered a "sexy young woman." I could use this to my advantage. I found men of all ages to be malleable. An extra long glance, a smile, a brush of the hand and they were like putty. No one was going to know about

the sticky green mucus of my insides; I hated it, and so in order to cover it, I began to make myself as beautiful and desirable as I could.

I began nesting a tangle of self-doubt and self-loathing even as I learned how to manipulate and use my looks to get what I wanted. As a child I'd avoided and thwarted unwanted male attention, but by fourteen I had discovered the thrill in catching the eye of an older man. They weren't afraid to look back, their palms didn't sweat, they weren't awkward or shy. I felt valued for what I was (pretty girl) when I garnered the attention of someone my senior. My mother warned, "They don't like you like you think they do." I didn't understand. Of course they did. They liked me exactly like I thought they did: desirably. Desire or lust in some fellow's eyes meant I'd succeeded, that my outside glimmered past the inner yuk. I felt wanted, loved, and beautiful.

1995

She takes a swing and she can't hit, she don't mean no harm, she just don't know what else to do about it

By my senior year of high school I had a handful of friends who had their own places. Bald Jeremy's was next to a roachy pizza place on a street infested with hookers, winos, and other denizens of the smarmy South Bend street life. I'm amazed with our bravado in those days. Walking down streets not meant for suburban white girls, preening for the men who cat called, asking for drugs, going into the homes and cars of strangers to get them. I can't believe we were never hurt; I think of how many ways we were hurt: taken advantage of, exploited, used.

I met Seth eight months after I'd decided to become a born-again virgin. I'd begun to grow weary of the meaninglessness in my interactions with boys. I was seventeen, heading soon for college. I wanted a fresh start. No more dabbling with older guys, no more sex with bad boys; I wanted love. I had succeeded in creating a persona of wild, sexy bad girl, but I started to envy my friends who had boyfriends who bought them flowers and took them on dates. I had visions of a relationship like the romance between Lloyd Dobler and Diane in *Say Anything*, of "Romeo and Juliet."

That last summer before college, my girlfriends and I had plans to follow the Grateful Dead. We wore second-hand clothes and ate lots of acid. My hair fell to my waist. I carried a one-hitter and a camera in a straw tote bag. I stopped shaving my legs. We were eighteen and free. It was the summer of my first true love.

I remembered Seth from high school. He had twirly eyes, like a cartoon character. I would see those kind of eyes only one time more in my life, in the eyes of a meth head in New Mexico, ironically also named Seth, who wanted a ride. The eyes would scare me. Seth's eyes scared me. I'd heard the rumors: that he smoked crack, that he had sex with lots of girls; they all said he was wild. I'd never really paid him much attention until one summer evening at Bald Jeremy's.

Like most teenagers' first apartments, Bald Jeremy's was sparsely furnished, the sink always full of dirty dishes. Band posters were tacked about the walls and the company was transient. People who weren't even really friends with Jeremy would come by, his house one of the few to hang out in where there were no parents present. Erica and Lola, my closest friends, and I were frequent visitors, being friends with both Bald Jeremy and one of his roommates. We'd flounce into Jeremy's unannounced in our gauzy

skirts and sprawl across his couch assuming that our presence was always a welcome addition.

One night Seth slinked into the house and fell into a threadbare chair across from me. His energy was like honey, syrupy sweet. His hair was a tangle of auburn curls. He was shirtless, his chest flat and hard, bare. His army pants were pulled so low that the V of his pelvis was exposed, soft auburn curls peeking from the waistband. He rolled a joint, meticulously folding in the corners of the onion skin paper to make little pockets, then tapping out a sprinkling of cocaine from a magazine folded bindle he kept in the cellophane of his cigarette packet. I wasn't even sure if he was aware that I was there. We all smoked: Seth and his friend Jake, Bald Jeremy, Lola, Erica, and I. We passed the joint from fingertip to fingertip, the raucous vibrations of Phish's "Run like an Antelope" wafting from an upstairs bedroom, the windows open to the humid summer air and the rattling mufflers and loud voices of the downtown street life. Soon after, Lola, Erica, and I went for a walk on the East Race, a pleasant boardwalk area built around the St. Joseph river. Our gypsy chains jingled, our patchouli drenched skin was soft in the lamplight as we discussed Seth and the cocaine laced joint and whether or not we thought we felt any different from it.

I decided to call Seth "Jim Morrison" in code because of a picture I'd had of the singer on my bedroom wall with the same wild wavy hair and low riding pants. I recruited Erica to help me track him down the next day. We found him on Van Buren Street, in the heart of run down South Bend, lying on a mattress in our friend Ray's bedroom, smoking a joint. The four of us drove to Rum Village, a park and nature preserve on the southwest side of town, where we swung on the swings and smoked a

joint in the woods. Seth massaged my shoulders from the backseat of my car as I drove us back to Ray's and asked me to come over and go in his hot tub that night. I agreed and snuck out of my house via the sliding glass deck door to meet him at the end of my driveway. He picked me up in his white Honda Civic, a cigarette in hand, Jane's Addiction on the tape player. My legs glimmered, slathered in the smoothness of Bath and Body works liquid talc.

Soon after, before we'd actually solidified ourselves as a couple, I left to go to Freshman Orientation at my new college, Ball State University. I thought about Seth the whole time and told my temporary roommate Alicia that he was really my boyfriend. I phoned him the minute I returned home. He said, "I have something for you." I picked him up and he directed me to the Park n' Shop parking lot where he pulled another bindle from his cigarette cellophane and cut a few lines of cocaine on one of the cassette tapes I had in my car. We took the innards out of a BIC pen to snort them up.

"Will I be able to drive?" I asked. He laughed.

"Am I going to have a heart attack? What if I'm one of the people who are allergic to this stuff?"

"Just do it," he commanded. I did, trying to turn my face away so he wouldn't see the pen up my nose. There was a burn and a numbing sensation and a little paranoia. But that was it. My first line of cocaine. The line that would change the next decade indefinitely. Though I didn't get the rush from the drug that I'd expected, I loved how wild I felt with Seth. I felt completely unabashed. I thought we made the perfect couple and I fed off his bad-boy image.

A week later I quit my job. I'd been working as a file clerk in my step-mother's OBGYN office for the last two years. It was a great job. I was paid well and they were flexible with my hours. My parents were infuriated. I was supposed to be saving money for college. Instead, we gate crashed at the Deer Creek Dead show and slept outside under the stars. We ate mushrooms and smoked pot. We did cocaine. We smoked crack. I learned that pay phones in the ghetto only allow you to dial ten digits before the type pad disconnects so you can't page people; that you use inositol powder to cut cocaine; and that yellower and chunkier is better. We talked about trying heroin. We watched Perry Ferrell shoot up and pretend to be Dr. Rockstar in *The Gift*. Seth wore my dresses and let me put make-up on him. We had sex in the car, behind a church, in my mother's house and his father's, in the woods, in bathrooms. We took Xanax and drank microbrewed beer. We played pool and went to the beach. It was an intense summer. I was in love. Then he kissed a girl named Vanessa in his hot tub. And the boy I should have let go, of moral failing and intense addiction, I began to cling to even harder. I sobbed the night before I left for college and ate three of my mother's Xanax bars. My heart was breaking.

When I got to college, still dating Seth long distance, I stopped smoking pot and started taking aerobics. I had the realization that no one was going to look after my health except me. I still drank, took hallucinogens, and did cocaine when we could find it, but I had this grand idea about saving my lungs. I didn't tell anyone why, I just told them I was "allergic" to marijuana. This was an acceptable answer. I hung out with hippies, bike thieves, druggies. Of all the people I was friends with in college, only a handful ever finished. Of those who did find success, many took the same roundabout path that I

found myself on. The lure of Phish music and freedom was so enticing that working the midnight shift at the BP didn't seem like a bad gig if it meant you could get all fucked up after and have no responsibility in between. I envied those people. Though I dallied in these fringe groups, I still felt a great deal of pressure to succeed both from my family and intrinsically. I was not going to fail at anything. So I compartmentalized. I could be smart; I could make Dean's list and still stay up all night on cocaine. I further compartmentalized my CF. I'd left behind most of the people who'd known about it from my childhood, and told fewer and fewer people. I didn't even tell my college roommate, Maria. Despite being friends in high school, it was several months into living together that one day she noticed me taking medicine before eating and asked me about it. I had no choice except between lying and telling the truth. I opted for the truth. I was embarrassed and played it off as nothing to worry about. I don't remember telling her about the life expectancy, though I know I often threw that number in, especially as I got older and surpassed it, as a means to prove how unaffected I really was by the disease. A few years later I recall asking Maria about that day and what it was like to live with me during those years.

"Yeah, I do remember when you first told me that you had CF. It was at the very beginning of living in the dorms at BSU. Ryne and I were both there. I think the reason it came up was not about coughing, but as a way to explain why you were taking pills before eating. It was the first time I had ever even heard of CF," she recalled as we mulled over a bottle of wine.

"I'm sure you told us all about it medically and stuff, but the part I remember most was you saying that most people don't live past 16, which sort of freaked me out. I had

never really dealt with the mortality of a close friend. Eighteen is quite an invincible time for most.

"I remember after knowing, feeling protective of you when you would cough... I remember feeling pissed at people who would be like 'Whoa dude, are you okay!?' Or, 'Damn girl, have another cigarette!' Shit like that, but I would use my lack of concern to try and show them that they were dumb for asking: they should do the same. Looking back, I guess they weren't assholes, just concerned, but I felt sensitive to what I viewed as tactlessness and sort of a MYOB situation."

Despite not smoking and exercising, two purposeful choices aimed at taking better care of my lung health, I still lived hard. College is a rough time for many coeds; binge drinking and crappy eating are commonplace, and I was no different. I was also warped into an increasingly codependent first love, something akin to a toddler in a Christmas tree shop: excitement, bright lights, and inevitable shattered glass.

Spring semester, Seth followed me to BSU and lived in the same residence hall on the floor below me. We spent most our nights in one another's rooms. He peed in an empty two liter the nights he spent with me; I lined his trashcan with a plastic bag the nights I spent with him. Though I was modest around his roommate, Maria, Seth, and I were all comfortable with one another and often the three of us slept nude, Maria in her bed, Seth and I crammed into mine talking late into the night. There was something uninhibited about being so uninhibited and I found us all quite bohemian.

I wrote Seth's papers for him, he rode me to class on the front of his bicycle. For spring break we headed to the Gila Mountains of New Mexico and the peaks of

Breckenridge, Colorado with a slight detour to Palomas, Mexico to purchase and smuggle in valium. We both fell in love with the Southwest and vowed to return.

Jealousy had slyly sunk its fangs in our young love over the course of our time together. Less than a year into the relationship we'd both cheated on one another; it's hard even now to understand why we continued to hang onto each other so fiercely. There was a sexual possession between us that I had never felt before and I wanted no other woman to have my man. It didn't occur to me then that I wasn't holding Seth responsible for his transgressions.

One night, post spring break, we were at a party at Sushi Goldfish's. Sushi's house was a staple in our night life. Sushi had gone to high school with us, though a few years older. Born of Russian immigrants, he had his own apartment paid for by his father even when we were still in high school. In college, his house was notorious for nitrous parties and cocaine nights. Sushi stole bicycles from campus and paid his friends in marijuana to work at night sawing the kryptonite locks from the front tires. Most nights at Sushi's centered around Southern Comfort and Euchre. One Sushi Goldfish night (they blur), my Euchre partner was a local Muncie boy named Martin. He was rude and paid me little attention save for occasional card talk. I found myself both frustrated by and attracted to his lack of attentiveness. The card game became hazy as more and more Southern Comfort was slung back. It became more of an exercise in the ability to focus on the cards by only using one eye than an actual game. Lola had already been lost to inebriation and vomit, Maria and I were not far behind. My last clear recollection of the night is my head perched over a trashcan with Southern Comfort

vomit sluicing out of my nose while Seth whispered vehemently in my ear, "You whore; have fun fucking Martin."

I awoke on Sushi's couch flanked by Lola on one side and Maria on the other. We walked home shading our red rimmed eyes from the early morning central Indiana sun. We met Seth in the courtyard of the dorm. He put his nose right up next to mine and hissed that I needed to return his ring. I didn't even remember him slipping the gold pinkie band I'd bought him after we'd both become enraptured with the gangsters in the movie *Casino* onto my hand the night before. I curled my fingers into my palm and said no. Seth grabbed at my elbow; I pulled back. He jerked my arm roughly and wedged it in close to his body trying to pry the ring from my finger. I bit his hand and he kneed me in the stomach. I went down with a gasp and he sat on my chest and pulled the ring from my hand. An off-duty fireman pulled to the side of the road with a squeal of tires and rushed towards us yelling. He pulled Seth from my chest. Soon after I found myself in the back of a police car making a statement and Seth was arrested for public intoxication and domestic abuse. Though I declined to admit that he'd kneed me, the fireman witness was all the state needed to prosecute. I visited him two times the one day he was in jail.

Soon after the arrest, Seth applied to and was accepted at the University of New Mexico for the following fall. His parents had always had the belief that if there was trouble, remove yourself as far from it as you can. Once again we were parting ways, and despite the lunacy of our relationship, I was again distraught and broken hearted.

Seth and I visited one another each month after he left for New Mexico, once each driving ten hours to meet in Oklahoma for the weekend. I began the paperwork to take out loans to transfer to the University of New Mexico that spring. My parents were

vehemently against the idea, Seth becoming nothing more to them than an impediment to my future successes. They truly feared that I would elope or become pregnant by him and bind myself to him even more fully than I already had.

Weeks after arriving in New Mexico, Seth began using heroin. I was both distraught and intrigued. I vowed to clean him up when I moved out there, but inside I was slightly jealous. I didn't want him to experience anything new without me at his side.

My father, Seth, and I packed up my Toyota Corolla in January of 1997 and drove through the worst snowstorm the southwest had seen in years from Indiana to Albuquerque. My father had succumbed to the fact that he was helpless against me leaving, but he'd at least get me there safely.

The temperature was in the negatives as we drove through the Midwest. Not far out of Indiana we suffered a tear in the sidewall of the tire. Seth and I stood helplessly aside as my father unpacked the entire trunk of the car and attached the spare with his bare and frozen hands. The blowing snow and slippery conditions of the roads as we headed farther south convinced my father that only he should drive and we listened to him lament, "This isn't good, this isn't any fucking good" as he inched the car along the Texas highway.

New Mexico quickly became an exercise in addiction. My grades dropped to B's. Retrospectively, this should have been a warning sign to my parents that something had gone amiss, but a B was still an acceptable grade and no one worried much. The truth was Seth and I spent some days awake on cocaine and some days in a groggy stupor of

heroin. My resolve to help him with his addictions dissolved hours after I put my father on a plane back to Indiana.

We made friends with another couple and they were among the first new people I told that I had CF in years. I had no other answer but the truth for why I coughed so incessantly sometimes. Cocaine constricts the nasal passages and some nights the post-nasal drip would cause me to cough and gag without end. As with Maria, Seth was protective of me when someone joked about my coughing. He may have been the one who told them, in all actuality, as a response to some joke such as, "Maybe you need to see a doctor for that cough?"

"What does it taste like?" asked one of the friends. "Is it like when you have a cold?" I had no answer, my sputum always tasted the same; in effect, I always had a cold. I realized that their curiosity wasn't a bad thing, it wasn't a force of pity but rather a simple desire to understand. Talking was much easier with the fuel of drug-induced stimulation.

I knew that New Mexico wasn't a healthy place for me to be. I never saw a doctor when I was there, I did not exercise, I was not eating well. I was clearly abusing drugs. The little cricket voice of my subconscious also knew that starting out my life with thousands of dollars of student loans wasn't as good an idea as going home and letting my parents pay for my education. Seth scared me as his addiction spiraled farther and farther out of control and I was grasping at twigs trying not to follow him down. It was still important that I remain above water with my school work. The final straw was twofold: a worried phone call from my grandparents one week after we'd unplugged the phone and stayed in bed on a heroin binge, and a family trip to France that was held

above me like a carrot on a stick: come home and you can go with us. My choice was made. After one semester and thousands of dollars, I was going back home.

1997

I'm funky not a junkie but I know where to get it

When I left New Mexico, I thought I was escaping something dark. I was oblivious to the ominous cloud of addiction that seemed to follow my Toyota on its return journey from southwest to Midwest. A mere three months later, Seth, too, was back and so, ever immersed in our dysfunctional version of love, I declined my acceptance to I.U. Bloomington and instead opted to stay in South Bend and live with my mother. It was a rocky year for Seth and me as a couple, and we officially broke up in May of 1998, right before I turned twenty-one. That spring he'd traveled to Breckenridge, this time with his brother, and there he met a new friend named Curt, a local man who ran an elite crack house back in South Bend. Curt's establishment flew in the face of anything the media ever portrayed about crack cocaine. Young professionals in business attire littered the apartment amid Peruvian exported furniture and high-powered entertainment systems, all puffing on glass test-tube pipes. I didn't want to hang out at Curt's. Smoking crack was not something I wanted to be a part of. Though I had tried it with Seth, I never liked it, but Curt's was the only place Seth wanted to go. As he spent more and more time there, I got a job as a cocktail waitress in a restaurant bar to keep myself occupied.

As soon as I turned twenty-one, I started to go out dancing at night. The bar scene fulfilled a need in me. It was fun, I felt pretty, and I didn't feel lonely. Seth was

three months my junior and wasn't legal to come to the bars yet, so it was an easy way to distance myself from him, not that he would have tried very hard to go far from Curt's apartment anyway. Ultimately, our break up was as ugly and unsettling as the entire relationship had become, and included a fat lip on my face. I was ready to be done.

I met Doug while I was waitressing. We started to go out dancing together at night. He was cute, but not my type with his thin Mishawaka moustache and his crotch rocket, but he was new and he was different. He worked as a non-union mason during the days, waiting tables for extra money at night. We often danced at a small club called Studes, a rougher dance club, popular because it played the best dance music. We made a good dance team and enjoyed one another's company. We went to dance one night at Studes; Doug slung his arm across my shoulders as we maneuvered through the crowd, our cups held above our heads, beer dribbling down our wrists. As we made our way to the dance floor, Doug stopped to talk to an older Hispanic man named Dave. They'd worked together on a masonry job. As we walked away, Doug whispered into my ear that Dave was a "total coke head." I had been drug free since breaking up with Seth. Seth had been my own personal drug dealer, the one I could send out in the middle of the night for more. I'd never fended for myself and the thought hadn't occurred to me that I could. Looking at Dave, a light went on, just dimly, in the back of my head.

The next week I was at Studes again, this time alone, when Dave appeared. I don't remember how I made it happen, but what I can remember is sitting in front of his house cutting a line of coke on the interior mirror of my car while he went inside to see if it was OK with his teenaged son that I come in. It was, and I did, and we all ended up playing rummy and snorting cocaine until the sun came up. When I left, Dave tried to

kiss me, but I turned my head saying "Thanks, it was fun" and drove home. Not much later I saw Dave wanted for attempted murder in the newspaper. His son was later arrested for a hit and run of an off-duty police officer, his blood infused with alcohol and cocaine. This was the beginning of my new life in South Bend.

There is a certain blur of that year from 1998 to 1999, but what I remember looks something like this: crystal meth, dilaudid, heroin, cocaine, cocaine, cocaine. And Xanax, lots of Xanax. Finding Dave was the stepping stone that opened up a willingness in me to fend for myself and find what I wanted. Once I started using by myself and taking it upon myself to get my own supply, either through Seth or through a network I was building on my own, I'd adopted a lifestyle that left no room for me to worry about anything else. Using drugs made me feel good, it let me forget my unhappiness and it felt like validation that my body could handle anything anyone else's could, maybe even more so. The drugs covered up my loneliness and let me embody the rockstar persona that I'd worked so hard to create. I could push my CF body to the utmost limits.

Sometime around December of '98 I became intensely aware that Kyle, my manager at the restaurant, was hitting on me. He'd smoldered at me my first day of work and I'd used his desire to my favor when he was the manager on duty after a table of men walked out on a hundred dollar tab. There was a "Days of the Dead" Halloween celebration at the restaurant that I was off duty for and I met my dad for a drink in the bar. We drank frozen margaritas and watched Kyle flirt with a TV news reporter. When I walked past him, he yanked on the back of my ponytail and smiled at me.

"All that guy is interested in is pussy," my dad remarked as I slid back into the booth.

Sometime soon after meeting Dave and forging my own connections in the underworld, an unknown illness hit me and sapped me of my strength. I was exhausted from the moment I awoke until the moment I was able to crawl back into my bed. I could make it to my classes - I had never uncompartmentalized the girl who succeeded at school. Despite the drugs, the mysterious illness, and Cystic Fibrosis, I never received less than a B in all my undergrad years, but for those few months, I would rise for class, trudge in in my pajamas, and then immediately come home and sleep for the rest of the day. I was tested for everything possible: meningitis, mononucleosis, strep throat, auto-immune disease. Nothing was conclusive. Deep down I knew it probably had to do with the lifestyle I was leading. My father bought me a basket full of herbs. I got a prescription for painkillers for my headaches. In late February I went to Indianapolis with my parents for my brother's state swimming competition and nearly swooned in my seat. Ever the party girl, while I was in Indy I tried to go out with Ryne, my friend from Ball State, on Broadripple, a street bustling with clubs and bars. Instead of having fun, I ended up vomiting in the bathroom of one of the bars. I was miserable but had no idea what was wrong with me. When I got back into town there was a call from Kyle inviting me to go out drinking with work people after our shift the next weekend. Despite feeling awful, I agreed.

The following weekend, the night shift bar crew caravanned in a mess of rusty cars, many with empty car seats in the back, to Bremen, a small town south of the city where Kyle lived. We met up at a tiny bar called "Sam's." There was karaoked "Love by the Dashboard Lights" and not enough empty seats at the bar. I had to stand. I didn't let on to anyone how poorly I felt, but after two drinks, I felt a blackening around me and

the floor rushing up to meet me. I managed to hold onto the bar and stagger back to Kyle's where I was able to sit and sip water and try to play a game of cards before I drove home. Clearly, I was still unwell.

Kyle asked me out for drinks the following Friday. He was in his forties and divorced. His left hand had an ugly mole on it. He wasn't especially attractive, but he looked at me with obvious desire, bordering on the need for possession. I don't know why I wanted him to like me. It was as if I was fourteen again playing eyes games with older boys. I told him I used to shoot up heroin, that I'd had a drug problem. I wanted to shock him, make a fire rise. A week later we slept together on the floor of his apartment. The minute he ejaculated, I knew. I had not had a period in two months from drugs or being sick, or both - but I knew. "Why did you do that?" I asked, angrily. "Do what?" he asked, rubbing his belly in an after-sex haze.

"That!" I sputtered, gesturing wildly toward my pelvis.

"Aren't you on the pill?" he asked, a slight incredulousness rising in his voice. I felt a sense of dread, a flutter of excitement, a tiny sparkle in my abdomen. In all the years of denying my disease, I'd always seen motherhood as the epitome of normalcy and defeat against CF. If I was pretty enough to have men find me attractive and healthy enough to bear a child, then certainly I had won. I had entertained the idea with Seth once. We'd even taken a month off of the pill just to see what would happen. When my period didn't come, I panicked and bought a pregnancy test. Suddenly the idea of motherhood wasn't as appealing when I was staring it in the face. I wasn't pregnant, and with that was a mild disappointment as well. Over the years I'd written journal entries that always maintained that I needed to keep my body healthy so that I could have

children one day. I hadn't really thought much about the idea since the debacle with Seth, though I know I still held the idea deep within that pregnancy would be the climactic fuck you against Cystic Fibrosis, another hurdle they'd told me I probably wouldn't be able to jump. It would prove in a way no abuse of my body could refute that I was stronger and braver than any expectation ever written about women with the disease. I was as normal as the next girl and in fact could live life harder, faster, and better than anyone ever would have expected. Even through the drug use, I always knew that I wanted to be a mother. I'd journaled about the idea frequently over the years, often lamenting that the one reason I felt it was important to stay healthy was so that I would be able to have children. I didn't mean to get pregnant, though I can't dismiss that subconsciously I wasn't averse to the idea. Kyle wasn't the ideal sire, but he'd do. Thirty-four and a half weeks later, Augustus Orion was born to me, and to me alone.

1999

I'd rather laugh with the sinners than cry with the saints, the sinners are much more fun

Hospitals are eerily quiet at night. The incessant squeak of cart wheels and beeping monitors slows from a panicked crescendo to a strangely calming cadence. The lights in the rooms and halls are dimmed save for the fluorescence of the nurses' station and voices are hushed to a whisper.

The story of Gus's meningitis is part of his legacy, a tale we now tell around the dinner table: how at ten days old his tiny scrotum swelled up hard as a rock and the pediatrician immediately put in a call to an urologist who rushed right over to the office

that Sunday morning. The urologist suspected a possible torsion, a twisted testicle that had lost its blood supply. Worst case, he'd lose his testicles. There would be prostheses and hormone therapy. I was in shock and terrified. My ten-day-old boy was at risk of not being a boy any longer. An emergency surgery was set and I rushed Gus from the pediatrician's office to the emergency room. My mother, step-mother, and I agonized in the surgery waiting area. I refused to speak to anyone, snapping responses at my mother and preferring a tense silence to hypothetical small talk. Finally, a nurse appeared and reported that Gus's testicles were fine, but there was an infection in the scrotal sack. The doctor was unsure of how it got there and what caused it, so Gus was admitted that night to the pediatric ICU with an unknown infection.

After a week in the hospital in South Bend, the decision was made to transfer Gus to Riley Children's Hospital in Indianapolis. No one in South Bend was able to figure out what was wrong with him. Despite the infection in his scrotum clearing up, he was still running a fever. Another week in Indianapolis complete with MRIs, CTs, BAER, PICCs, lumbar punctures, sleep studies, car seat studies and a room at the Ronald McDonald house resulted in a diagnosis of bacterial meningitis and six weeks of intravenous antibiotic therapy. The infection had spread to Gus's liver and his brain. If the infected spot on his brain did not respond to the antibiotics, he would have to have surgery in order to relieve the pressure in his skull.

I didn't handle having a sick baby well, but I applied the only coping mechanism I'd ever known to work against health issues: denial. I pretended that nothing was wrong with my son. I knew he would be fine. I had trouble with the lack of control that a hospital affords to a parent and often butted heads with the doctors, nurses, and

technicians. Doctors never held high esteem with me; I blamed them for my own disease and had trouble allowing that they were, in fact, saving my child's life. I threatened the nurse who had trouble starting one of his numerous IVs; I argued with the residents about letting the baby sleep and reminded them that I, not they, was the one in charge. I feel great shame and embarrassment at my behavior when I think about it now, but I know deep inside I was terrified. Gus was a gift I'd never thought I would have, but I was still so selfish. I wasn't ready for the responsibility of taking care of another human and my heart was unprepared for the burden of loving another person so deeply that it hurt.

Once the infection in Gus's brain began to resolve, we were allowed to return home to finish his antibiotics locally. I wanted to resume my classes. I was in my last semester of college, having only my student teaching left to do before graduating, and I already knew I would have to take incompletes in the classes I was finishing when Gus was born. Once we returned, I was balancing going to class and making up my school work with being at the hospital. At Riley I had ended up taking a room at the Ronald McDonald house. The hospital was too frenzied at all hours and each room of non-infectious patients housed four children at a time. There were no beds in the rooms, only vinyl fold out chairs. After a few sleepless nights I was too exhausted to be of much use and ended up sleeping in my room at the Ronald McDonald house.

Once we were back in South Bend, Gus had a private room with a crib and a bed in it, so I was spending most nights in the hospital. He was the smallest and the sickest baby on the peds floor and received an abundance of love and attention from the nurses. Once the worst had passed, I was able to relax and even enjoy the company of some of the medical staff.

Gus was hospitalized over Thanksgiving and on the Wednesday night before the holiday I decided to stop by the bar on my way home from class. Gus was in good hands, and I believed I deserved a break. As soon as I walked in, the smell of stale cigarettes and exhaled alcohol brought on a wave of nostalgia. I didn't realize how much I had missed the bar scene during my pregnancy and early weeks of motherhood. The music and laughter and clanking of bottles stirred a feeling in me I hadn't realized was so strong. I wanted more. I wanted to stay there in the hazy air and pretend that everything in my life was fine. Seth and his brother were there. They bought me a beer and asked about the baby. Seth handed me a bindle of cocaine under the table and said, "Happy Thanksgiving." I don't know why I didn't say no. It would have been so easy to pass the packet back to him and tell him how much I appreciated the offer but that I had a sick baby in the hospital. But I didn't. I wanted that packet. I wanted the relief that it would bring me, the temporary elation I would feel that would make the worry and hurt disappear for a while. I wanted to be "me" again. I wasn't sure how motherhood fit with my self-image. I suppose I wanted the best of both worlds. So instead of declining, I took the bindle back to the hospital with me. My shame is so palpable I can hardly write about it now, but the fact remains that I did lines of cocaine in the bathroom of my son's hospital room, taking my breast pump in with me lest a nurse look into the room and wonder where I was or what I was doing. I can't remember if I dumped the milk I pumped. I would certainly like to remember it that I did, but I don't really know. I know how badly I felt that day, but I feel far worse about it now. I was twenty-two and selfish and nowhere ready to be a mother. I can forgive myself the selfishness of having unprotected sex and bringing a baby into the world without a father, but the anguish I feel

knowing that I'd allowed this lifestyle to become so ingrained in me and that I had become so defined by drugs and alcohol that I lost my ability to make good judgments is still tangible. I hated myself.

I stopped nursing Gus right before Christmas. Which is a good thing, as in the pictures I have of that New Year – Y2K – my nose is red from the itching the heroin gave me and from the cocaine I used to counteract the nausea. There I am in a pink sweat suit, holding my baby on my lap, red nosed, eyes glossy and half open. I wrote this in a journal:

Gus slept for four hours last night but I was too coked up to enjoy it and he'll probably never do it again. I've been getting high a lot, plus Seth got a hold of some heroin and I did some coke and I've just felt like a fiend since. So it's true you just pick up where you left off because each binge is more intense. The thing is, I can't afford it this time; and I use afford in more than just a money sense.

I have to allow myself credit for loving Gus. I never hit him or left him in a dirty diaper. He never went hungry; I never let him cry himself to sleep. He had nice clothes and toys. I loved every inch of my child, but I did not understand the importance of my role as a mother. I thought mothering was something that would be natural and easy. I postponed my student teaching for one semester and took the spring semester off to finish my school work from the classes I'd missed when Gus was in the hospital. I also didn't want to send my two-month-old baby to daycare. I had enough money from scholarships to put gas in my car and other frivolous spending. My mother allowed me to live rent free in her home. Gus had Medicaid and WIC and, because I was still a student, I was still on my mother's health insurance plan. Financially I was OK, but I wasn't prepared

for the boredom of being a stay at home mom. At nap time I would smoke a joint (I'd given up not smoking once I had returned to South Bend), throw Gus in the car seat, and drive around town listening to music. I would plan trips: drive past all the schools I went to; drive past my best friends in elementary school's homes; drive past all the houses I'd lived in in South Bend. Gus would sleep and I would enjoy my "alone" time in the car with the music. I started drinking at lunch. Seth would bring me 20 sacs of coke on his way to the bar and I would snort them up by the light of my closet while my son slept in my bed. By day I was a mom. By night, I was still just a twenty-two-year-old party girl.

2002

If I leave here tomorrow, will you still remember me?

I remember telling George I had CF, but I don't remember telling him about the cocaine use. I know I'd squeezed the idea into early conversations to determine his reaction and he'd said that it wasn't something he was into because he believed it had destroyed the life of one of his brothers. After hearing that, I kept mum on the issue and made the assumption that he wouldn't find it odd if I disappeared into the backroom of the tavern or covertly exchanged money for bindles passed hand to hand over the bar.

I met George just two weeks after my step-sister was killed in a car accident. I'd had a terrible time dealing with Elaine's death. She had had a severe seizure disorder and was on high doses of neurological medicines for most of her life. Due to this, coupled with some brain damage from frequent and uncontrolled seizures, she was slightly awkward. Today maybe they would call it Asperger's, but then she just seemed a beat or two off. As a child I was embarrassed of Elaine. We went to summer camp together and

she didn't brush her teeth or shower the entire week; Cheetos smushed into her braces. My step-mother tried her on a ketogenic diet as a cure for her epilepsy and she became sickly thin like a sick Ethiopian child. I was annoyed by her lack of coolness, the way that she copied the things that I did. I easily manipulated her trust and naiveté to my liking. As we grew older I no longer found the need to torment her; we just started to ignore one another. Before she died she'd met a boy and fallen in love. I was so happy for her, but I never told her so. I'd outgrown all the petty issues of my childhood, but I'd never apologized for the hurts I had inflicted in our childhood. This guilt became my cross to bear following her death.

Elaine's illness had been outward: grand mal spasmodic seizures. I knew that Elaine and I both suffered from disease; it was a commonality between us, but whereas mine was akin to an incestual secret, hers was loud and visible. I worried that if people knew about my CF they might assume that my disease affected me like Elaine's did her. I assume, looking back, that this must have influenced my unkindness toward her. She represented everything I feared about my disease. Though there were certainly good times between us, it was the bad ones that I let torment me after she died.

Two weeks after Elaine's death, I was finishing my first year of teaching, and despite the tragedy, looking forward to a summer without work. Gus and I had our own apartment, a tiny duplex in front of a double set of railroad tracks, and life seemed happy. I dated off and on, but no one special. No one I brought home to meet my son; no one I told about CF. If I had a lover, I learned how to hold my coughing in until I could escape from bed to bathroom where I would stuff my face into a towel and cough as hard as I could hoping I was stifling the sound.

My mother babysat for me every Thursday night and almost every Saturday, so my social life did not suffer much from being a single mom. I'd taken to hanging out at a local bar where I had become friends with the bartenders and even worked some nights tending bar or cleaning up. It was a frequent stop on the South Bend underground for drug deals and petty criminals and I loved it.

Meanwhile, I was also becoming successful as a teacher. I felt the children truly liked me and that while pedagogy wasn't my strong point, empathy and love were. I felt I could love them each individually and help them find themselves in the mess of who they were "supposed" to be. I spent many classroom hours counseling and coaxing out creativity. Standardized testing be damned, school was meant to inspire! Still, I spent nearly every Friday hung over. Some nights I would not have even slept before work, showering and brushing my teeth to hide the scent of the bar and washing down a greasy McDonald's sausage and cheese biscuit with a big syrupy Coca-cola on the way to school. I don't know if anyone ever noticed. I felt no one noticed my tired, puffy eyes and pale skin on those repetitive Friday mornings. All I knew was that I got up and went to work, just like I should. This meant I didn't have a problem. I took care of my responsibilities, so what did it matter what I did in my off time?

After Elaine's death, Erica had badgered me constantly about getting out and not shutting up in my house any longer. She decided we needed to dress to kill and go flirt with boys. I put on a short skirt and a pair of platform heels and off we went. We hadn't been in the bar for long when Erica started talking to a guy we both had mentioned we found attractive. He rode a motorcycle and wore a leather coat and carried the typical "bad boy" image with him that I'd always found attractive. What caught me off guard

was that standing next to him was a man I had never seen before. He was tall with a beautiful smile. I was immediately interested, and then embarrassed by my attire. I'd gone out planning on flirting and being silly. I did not plan on meeting someone with actual potential. George was employed, he was a father, he'd been in the Navy and had traveled the world. George and I spent most of the night talking to one another and as we parted ways I had a premonition that we would be something special. The next evening I was home alone going through a pile of Elaine's clothes that my step-mom had given me. It was an odd and emotionally taxing job, deciding what to keep and what to discard out of the pile of clothes. There was a soft knock and I was quite surprised to see George standing there when I opened the door. He asked me what I was doing and I stumbled over the answer biting back tears. He then shared with me that his own brother had been killed in a fire years before. The stars were aligned that night, as neither of us had a second thought about becoming a couple after that. George soon became one of few men that I deemed important enough to tell that I had CF; I knew I had to tell him if the relationship was as special as I'd thought.

Mornings after nights of cocaine and alcohol often reached suicidal proportions, not just from depleted dopamine reserves and hangovers, but also because of guilt. Where the night before I had been on top of the world, the queen of the bar, the next morning I was still the mother of a young boy. Often I was ashamed to look him in the eye when my mother brought him home, knowing that just hours before I had been doing lines of cocaine and drinking Mescal with my bar buddies at after-hours parties. I would not have slept yet and I would be so very tired. I'd lie around on the couch, nuke Gus a hot dog for lunch, and make nap time as early as possible. Sometimes a nap wasn't

possible and the blackening depression of the morning would be so great I would simply cry. If anyone had known my double life I feared I would risk losing my job, my child, maybe my home.

Early in our relationship, though I had grown to love George, I quickly realized that his presence hindered my bar antics. Often I was still able to achieve the best of both worlds - George's presence as well as a good cocaine-induced buzz - but the guilt I had to endure by not being completely honest hung over me. So I started to hint that it would be good for our relationship to have a night apart to spend with our friends. My line of thinking was that absence would make the heart grow fonder. The routine began that on Thursday nights he would go out with his friends and I would go with mine, and then we would meet up at his house after. I often arrived back at the house much later than George, and sometimes I would simply lie awake in bed next to him, afraid to move lest he know I was still awake. It was one of these dark mornings after a sleepless night that I confessed to George what I had done. I first told him that I was too sick to get together that night, but he was so concerned for me, not knowing that my illness was self-induced, I just couldn't live with my guilt any longer. I confessed, playing it off as a once in a while thing and I promised him that was the last time. I never, ever wanted to feel like that again.

For three more years I lied and hid my drug use from George. There was another morning I remember clearly. I was asleep on the couch and George came to pick me up for his son's birthday party, but he couldn't wake me. When he finally did, I was a complete mess. The night before I had called to tell him I was too fucked up to come over and would just be going home. It was true, but not from drinking.

I'd made a place for myself at the bar by this time. I was a regular; I often did not have to pay for drinks and I almost always stuck around for after-hours antics. Sometimes that was simply cocaine-fueled bar cleaning, other nights it was dice and music. That summer night, Bryce, one of the bartenders, and I had gone to some black fellow's house we'd met at the bar at 2 am to get more cocaine. I convinced myself that if I went home with the drugs rather than back to the bar, I would be in better shape for the birthday party the next day. I called George and left him a message and then proceeded to snort the cocaine by flashlight, at my house, alone, for the fear that George would drive by. Years later he admitted that was exactly what he did. The next morning as I looked into the face of this man that I loved and had even begun to realize I wanted to marry, I promised I'd stop. Again. George said, "You're a liar." I cried. He was right. I swore I would change, and I meant it. That day, I did.

What I learned from those episodes wasn't abstinence, but self-control. I finally learned how to pull myself away from the bar by midnight. Though there were nights that even coming home early I still found myself paralyzed in bed for fear George would know I was awake, watching the clock tick by in agony until I had to get up for work. There were even a few scary sleep-walking episodes caused by the mix of my anti-depressants with cocaine, alcohol, and muscle relaxers which I took with the hopes that they would make me sleep. In my mind, things were better, though retrospectively I can see that I was still a wreck. I was abusing my body and betraying the trust that George put in me when I'd promised that I would stop the bar room antics. I thought I'd learned not to choose cocaine over George (now my fiancé) and my family, but it didn't mean I wasn't using it.

It seemed things were going well. I'd met a man I loved, one that I trusted enough to share the biggest secret I had, my disease, and I had a good job. My life was going the way it should, or so I thought. Still, on the health front, I was disintegrating. I wasn't exercising; I spent a lot of my free time in bars filled with smoke; I used marijuana and cocaine and alcohol in excess. My doctor had become more aggressive in his dealing with me, but I know now from recent conversations that the entire CF team saw me as an obstacle to myself. They said it was like talking to a brick wall. I saw the numbers on the paper that showed my declining lung function, but I just wouldn't recognize it as truth. Despite the coughing fits I had sometimes during the day where my students would laugh nervously and say, "It sounds like you are laughing!" and, "Look how red her face is!" I never told any of my students or colleagues why I coughed. I just laughed it off as asthma or bronchitis. When I started graduate school that spring I learned to avoid other students on the stairs who would want to make conversation as we walked the three flights to the conference room where most graduate level classes were held. If no one saw me, I would happily resort to the elevator, an unspoken no-no on college campuses. Despite all this, the one thing I really started to want was another baby. *I've been sick. Sometimes I worry about having another baby,* I journaled, *like if I wait too long, my body won't be strong enough.* Despite my fears and the admission that I was being hard on my body, I felt that I could be such a better mother if I had another chance to do it right.

2007-08

Fucking, fighting, it's all the same, live as though we'll die is the only way to stay sane

The World Wide Web had become popular when I was in college. Only certain computer labs had internet access my freshman year, but almost immediately I'd become a secret computer geek. I visited chat rooms when chat rooms were still on a vax system, had a blog before blogs were called blogs. In 2000, I had joined a body modification site called "BMEzine.com" which was a "Facebook" before there was "Facebook" for the tattooed and otherwise body modified set. I also had a journal on a site called "Live Journal" that I wrote on sometimes during work, as I could not access the BME site at school. Via these sites I had internet "friends" I'd never set eyes on long before that was acceptable. Internet communication was not new to me, but it was many years into my internet activity before it occurred to me to use the tool to search for anything related to my disease.

One day in August of 2005 something prompted me to type "Cystic Fibrosis" into the Google search engine. I remember the secret shame I felt when I typed the words into the computer, as if I was looking at pornography or pictures of an ex-lover. I even looked over my shoulder to make sure no one had snuck into my empty classroom. I felt as if the students would return to their desks and my secret would be boldly written across the blackboard. I was lonely. Maybe I was sick. Whatever led me to file through the different entries regarding CF isn't clear to me now, but what I stumbled upon that day was an entire online community of people who were just like me: adults dealing with Cystic Fibrosis.

My visits to the CF website became increasingly frequent. I tentatively started to post threads in the forums and even began a blog hosted by the site. A few months later, I received a private message from someone named "Calidore." The message was benign enough, about a picture of one of my tattoos that I'd posted. I wasn't sure if Calidore was a man or a woman; I wasn't sure if I was being flirted with or just chatted with. In 2005 I was newly married and trying to get pregnant. Having left many of my male bar friends behind for matrimony, I was still surfing through new issues of trust and friendship with members of the opposite sex within the confines of marriage, so I was a little apprehensive at first. I didn't want to give anyone the wrong idea. While most people had tiny avatar pictures associated with their screen names, Calidore was just Calidore. Calidore and I messaged back and forth on the CF website a few times about religion and ahimsa and voices-in-our-heads and then the messages fizzled out.

I found my interactions on the CF website comforting. I had created such a them-and-me idea of the disease and my place within it that I'd never allowed myself to think that there might be people not unlike me with feelings much as my own out in the world. I started to visit the chat room at night. I didn't realize that I would enjoy talking about CF. And while the disease wasn't always the topic of chat, the subject was never closed.

One night in chat, a private box popped up with a chirp from Calidore. No one had ever messaged me privately before while I was in the chat room and I was surprised. He asked about my health and revealed to me that he was listed for a double lung transplant. Bringing up our previous conversation regarding my tattoo, he told me how part of the pre-transplant psychological evaluation asked if you "had tattoos and used IV

drugs" as if the two were mutually inclusive. Though I kept mum on that idea, I liked Calidore, and was flattered he wanted to chat with me. More importantly, he began to give voice to ideas that had not even completely formed in my head about life with CF.

When Calidore received his call for lungs, the CF forums lit up with good wishes and congratulations. I added my thoughts in, but my days were busy with marriage and graduate school and having a new baby at home. I didn't put a lot of thought into it. It was a few weeks, maybe even months later, that Calidore and I were both in the chat room; he was recovering in a motel near his transplant center, and someone called him the "Bob Dylan of the CF world."

"You're a musician?" I asked, my interest piqued.

"I try," was the reply. Calidore then sent me a private message with a link to his blog. When I clicked on the site it opened to a picture of a shaggy, dark-haired, unshaven man. He wore oxygen tubing that ran over his ears and under his nose and his chin was cupped in his hand. His fingers were long and delicate and slightly clubbed as happens to CF patients. His eyes were closed. The sepia photo held the weight of a thousand lonely nights. A woman with her hair held pulled back stood in a doorway in the background of the picture, unsmiling but not unhappy. She looked misplaced, at a loss, an onlooker. He seemed tired. I was intrigued. A further comment about an obscure band we discovered we both liked solidified the deal. From then on, Calidore became Don, his real name, and our friendship took form.

By the time Don had received his double lung transplant, I had finally gotten pregnant and had birthed a baby girl. From the first day of my pregnancy on through the first year of nursing her I was clean and relatively sober, save for a lone cocktail here and

there, often in the bathtub with a book or after the children had gone to sleep. I enjoyed my new found sobriety and began to find time to rekindle and further my knowledge of sewing, and I learned to crochet. I enjoyed this domesticity. I knew that I was using the baby as a way to protect myself from myself and my own destructive habits, but it was working for me. My pregnancy had coincided with my burgeoning relationship to the online CF community and through sobriety and my new friendships, I was starting to take a different outlook on my health.

Don and I began to write to one another almost daily and we often left the CF chat room for our own private "box" on Yahoo chat. It was the loneliness that initially connected us. I'd always been lonely, the kind of lonely that you just had to "get," the kind of lonely that I saw in Don's picture, though he wasn't alone. Lonely people do a lot to try to blot out the lonely and Cystic Fibrosis is a lonely disease. Don understood me immediately. He understood being alone, the joy of being alone and the desperate sadness. With Don I never felt alone, even when we felt like two of the loneliest souls on earth.

"Because I'm alone, alone, and I don't even know if I'm alive or dead: I could be dead, I'm on my own, inside my head. And I admit I kind of like the way it's been," Don sang in one of his songs. Eventually I came to learn that we were all alone and lonely in our little computer boxes, we lung-ers. The internet and the CF online community was an outlet for that loneliness, a way for us to be alone together.

My nights began to resemble one another that year. Around eleven, by the time I had read a few bedtime stories to my son and nursed the baby to sleep, George would be sprawled across the couch watching a White Sox game. Guttural noises emanating from

the room would let me know when he'd fallen asleep, despite a newly opened can of beer at his head and remote across his belly. I would sit in my home office, possibly a rum and coke perched on the rough drafts of some paper I should have been working on for graduate school. Instead I'd open my Yahoo chat box, click on the name "Calidore," and type, "You there?"

I'd been taking more and more liberties that Don would be there and he would want to talk. Since his transplant we'd been chatting most nights. The talk was easy; I was enamored with him. He was smart, witty, also an English teacher and a writer; we had plenty to discuss academically as well our shared disease. I felt that Don understood me.

Don kept a blog called "Transplant Nation." I didn't have to read very far into the writings to see that Don was talented. Soon I was completely smitten with the way he had with his words.

"*For the cystic*," he wrote in a blog about being part of a meditation group, "*this seems an advanced practice, more a Zen trial of mettle than a friendly introduction to one's own mind. For the cystic, who is always focused on his breath, this practice does not relax. Nor does it free him from the comparative references that leave his distorted self-image hard and intact. When I sit in a group, I am appropriately mindful of those to my left and right, each of whom deserves a quiet space in which to meditate. On good days, my chest is quiet. I don't cough or choke. But on other days, the orchestra starts up, I do cough and choke, and as much as I try, I cannot shed the awareness that I am disrupting others. I understand that the world is full of disruptions and that mindfulness practice includes being mindful of them, yet at such times I cannot escape my self-image,*

because it projects itself so insistently, so violently, on other persons. No one ever comments on it. These aren't the type of people. But they don't have to mention a thing, because the idea that I'm a 'bad breather,' that I belong alone in some other room and not in a circle, already exists in my mind. It is an interpretation I must learn to break through. It is the hardest part of my practice."

I was nervous to reply, afraid my words would sound bumbling and backhills. Still, I wanted to comment on his thoughts and I was immediately inspired by his poetic style.

Oh my friend, how you have nailed this. I think through all of my years of yoga practice, trying to be mindful of my breath has always left me more mindful of my lack of breath: how much more quickly I breathe than my cohorts, how my OM only resonates a quarter of the time of the others, how they follow the breath with each fluid movement: inhale up, exhale down - while ole Shan inhales exhales inhales up, exhales inhales exhales down. No wonder I hide from this disease as much as I do.

Understanding is an alluring quality, to meet that person who can tell you what you are thinking without asking, who has memories that mirror your own from his childhood; that person who could have been you if you were anyone else. The feeling of camaraderie and connectedness is hypnotic. All you want to do is be with that person, compare notes, revel in the profoundness of your shared thoughts. That was Don.

I loved my husband, but over the years together our differences had begun to grow rather than shrink and sometimes I felt a huge fence between us, especially on the subject of my disease. In defense of my husband, I had presented myself to him as healthy and made it very clear that my Cystic Fibrosis was nothing more than a blip on

the radar, certainly no big deal. As I became more involved with the CF community and with understanding my own disease, I wanted to talk about it with him more. I wanted to share my findings, but what I found was that my husband wasn't as available for discussion as I would have liked. I had become fascinated with this entire world I had ignored for so long and he didn't understand it. He simply saw the computer as an obstacle between us and my commentary on my health as "complaining." I saw the computer as a portal into a world that I had tried in every way to cut myself off from and that now gave me freedom to talk about my disease. I felt my time spent online as a means toward personal growth.

"Not many people get this stuff," Don wrote one night as we Google Earthed one another's childhood homes, compared dad stories, and talked about the extremes we went to hide our disease. "Do you think I get it?" I asked tentatively.

"Your user name is "WanderLost," how can you not get it?" Don replied. I felt proud and accepted.

"I'm gonna look you up sometime when you're all healed and I'm in Chicago," I wrote another night, this time as we discussed bands that we both liked. He was more into old time swing while I still preferred the funky girl and her guitar, though we both liked older country music: Merle, Waylon, Dolly, and the newer version of that, "alt-country."

"I got into Freakwater in college, so mid-nineties. I saw them once in Chicago, but I ended up drinking too much and having to sit down for a lot of the show. David Gay lit my friend's cigarette and they played 'Gone to Stay' per our request," I wrote.

"I spent my 30th sitting in the Dresden Lounge in LA smoking a Dominican cigar. It did feel strange. The median [age expectancy for CF] then was 29, and I'd passed it. For some reason, that made everything around me particularly vivid and worth observing. Just being alive and conscious sometimes blows my mind. Thirty was one of those times. The cigar was a challenge -- I don't really like cigars -- but the drink was tasty, and there was an off-key duo named Marty and Elaine playing Sinatra tunes on an organ. I was alone, cuz I was out there on business. But it was a great evening to be alone. I chatted up an old artist chick -- 39! -- and we wound up hanging out for a few days. In one evening, it seemed my life had turned into a Tom Waits song. And yes, I thought the same thing -- middle age. But 30 sure seems young today, and Tom Waits seems more full of shit!"

My heart sang with every word he typed.

It was soon decided that Don would stop in South Bend one night on his way from Pittsburgh, where his transplant center was located, to Chicago, his home. I approached the subject with George and he wasn't pleased. Meeting a person from the computer, a man no less, wasn't something people did in his world. I could not get him to understand that Don was different. He wasn't a man in the sense of a man and a woman meeting; he was a man with CF and the only person in the world who I felt truly understood me. It was almost spiritual. George reluctantly agreed that I could meet him.

I remember exactly what I wore: a new purple tank top my mother bought me. I braided my hair so that he could see the top of the tattoos on my back. I had on fitted blue jean capris and some brown leather Mary Jane wedges. I wanted to look how I imagined he imagined me: sexy yet maternal, pretty and funky. Dancing Earth Mother,

he once called me. Some make up, mascara, not too much. Lip gloss. Don and I didn't share a romance, but we'd had the "what if" conversation: what if things were different, what if we didn't have CF? There was the possibility that in some other life we might have been more than friends. The fluttering of my stomach on nights when "Calidore's" name popped up in my Yahoo box was real enough that I know there was something between us.

We decided to meet at a local coffee shop, a trendy, artsy place near his hotel that was also a safe, alcohol-free location. It wasn't that drinking was an issue, but I was smart enough to know that I was attracted enough to Don, mentally rather than physically, but enough to know that I should not let alcohol impair my judgment. Don liked me for me already. I had admitted to him before meeting that I flirted when I was nervous, that alcohol smoothed out my edges, and I didn't want drugs or alcohol to hide any part of me from this man. Not when he already liked me as I was.

I sat outside waiting for him, my nerves dancing. He was late. When I saw him walking over from the parking lot and felt panicked. Get up and run over? Call out his name? Pretend I hadn't seen him? He wore a green army coat with Barack Obama pins on it and carried a back pack. "Is that you?" he asked as he approached. "It's me." I answered.

We had talked about this moment, the meeting, before. He told me he didn't often look people in the eyes when he spoke. His awkwardness. He felt maybe he even had a touch of Asperger's Syndrome. We'd discussed how awkward we both often found social situations to be. How much trouble we had fitting in, the methods we used to compensate. "Ah, but in print!" he wrote one night. In print, online, we were ourselves

without the awkwardness of sitting face to face. Our words became us. Don had an exceptional way with words. This is what drew me to him. First it was the music, and then it was the words. Then it was only the words. And we could talk about the music, but words held the magic. It seems some of the most powerful reactions I have had are from the people I knew only by words. The ones that make it to my dreams are the ones whose words make love to my brain.

The coffee shop was close to closing and Don wanted to eat. It was necessary for him to keep his blood sugar as well as potassium and sodium levels at a steady number. The high doses of immunosuppressant drugs post transplant can make the rest of the body go wacky. He had already suffered massive edema that made his feet swell like balloons and some severe intestinal complications from the high doses of narcotics he'd been on, so Don was particular in keeping himself segregated from possible problem situations. This included me. We did not hug or even shake hands as my CF lungs still harbored bacteria that would not be harmful to his new, non-CF lungs, but could cause potential setbacks to his body due to his immunosuppression. He didn't want to ride in the enclosed space of a car together to look for a place to eat, so instead we walked down the strip of road from the coffee shop toward a cluster of fast food restaurants on that balmy Indiana July night.

The conversation started slowly, with easy bantering as we warmed to one another and assessed what thoughts we had about one another based on the internet communications and the real person standing in front of us. After finding one eatery after the other closed, we ended up at Dairy Queen. Don ordered Chicken strips while I slurped on an iced coffee from the coffee shop. Seated at the table we spoke of our

mutual online friends, his health, and mostly, life with Cystic Fibrosis. I felt my shyness shedding and I noticed he was, in fact, looking me in the eye as we spoke. We were eventually kicked out of Dairy Queen by the teenaged manager and I directed us down a quieter street on the way back to Don's hotel than the main drag we'd taken on the way to the Dairy Queen. Though we hadn't touched since meeting, as we walked, our shoulders bumped into one another a few times. The street was lined with row homes and goblet-looking street lamps. The night was silent save for our voices and feet crunching on the gravel as we walked. The air was thick and heavy. At one point I had to stop to cough. I bent at the waist and crossed my legs so that I didn't accidentally pee my pants as I coughed. I realized how unembarrassed I was by this. I had no urge to hide any part of the functions that my dysfunctional body forced upon me. Don looked on patiently, "That's Ok, go on and have CF," he smiled. As we resumed walking I looked at him out of the corner of my eye: his graying hair curled softly over the edges of his army jacket, his teeth were slightly misaligned; he looked like any average forty-two-year-old man. As I watched him while we walked, something almost magical happened: it seemed as though he was shining. It was like the moon and stars had bathed him in light, like being able to see someone's aura. It was a breathtaking moment and I had an overwhelming urge to wrap my arms around him and hold tight. It wasn't a sexual urge; it wasn't even a feeling of kinship so much as a feeling of absolute truth. Don and I were meant to know one another, we were meant to be walking together shoulder to shoulder down that silent back street. It was the only time in my life I have been convinced that I was in the presence of a soul mate.

We got back to Don's hotel and talked in the parking lot. I didn't want to leave, but I'd already been gone for hours and I knew that George would be unhappy, that the baby would wake soon and want to nurse. After the magical moment when we walked, any awkwardness that had lingered dissipated. We were completely comfortable in each other's presence, as if we'd been friends for years. We stood under the yellow streetlights comparing cellphone ringtones – his was Hank Williams, mine was Merle Haggard. We chatted about bands we'd seen and friends we shared online. We talked frankly about the path his health was on with the newly diagnosed rejection. The conversation was smooth and any tension between us wasn't from discomfort, but from the unsaid reality of how much we liked one another. He mentioned pulling out his guitar and playing me a few songs. I wanted to stay and hear them. I didn't want to leave, but I knew it was getting late and that George would be waiting for me.

"Go on, scram," he said when I mentioned I probably needed to leave. "I'll see you in the box."

I hated to walk away, but I went home to continue our relationship online, the same way it had begun.

A few days later we discussed our night together comparing our expectations to reality. I told him that he'd looked me in the eye when we spoke and he mentioned I didn't seem as shy or flirtatious as he thought I might be. One lesson I learned after Elaine's death was that I didn't want to leave things unsaid to people I cared for, so I especially wanted to tell Don just how amazing I'd felt spending time with him. I also didn't want to scare him or have him think I was crazy.

"You know when we were walking back to the hotel?" I typed. "Well, I just had this feeling, this….moment."

"I know," he replied.

"You do?" I asked.

"Of course, I was there too," was the answer.

"I just felt like we were meant to be together, like you're one of my soul people," I admitted. Don agreed. A few weeks later on my birthday I received this in my inbox: *You're an amazing cystic. I never tell you, but I'm always so impressed by all the things you do with such poise and equanimity. I'm glad you were born.*

2009

This train has got the disappearing railroad blues

In recovery programs they call them war stories. I also call it drug radar, the way I can pick out the user in a room almost instantaneously and when we connect, we share the stories. If we didn't know one another before, it's one-upmanship. "I broke down crack with lemon juice to shoot it up"; "I stayed up for a week straight on meth." If we do know each other, we talk about how bad, how crazy, we used to be together.

I was in Martin's Supermarket shopping late one night and found the girl behind the meat counter looking vaguely familiar. My drug radar began going off like a car alarm.

"Are you Erica?" she asked. Common mistake, my old friend Erica and I looked enough alike and spent enough time in the bars together that we were often mistaken for one another.

"Nope, Shannon. Erica and I hung out together though."

"That's right; you used to go with Seth Green."

"Ever see people from back then?" I asked while picking out my deli meat.

"Not too much; I try not to."

Yvette. I remembered her name then; she dated Jeff Hudson, one of the go-to guys in the bar scene for cocaine, before he got into the jewelry business. I was never positive where she stood with him but I remembered them often being together.

"I have a baby now," she replied while bagging my tavern ham. "Didn't you have one too?"

"Yup. He's ten now."

"I just can't go out anymore; I have to be a mom now," she said, handing my bagged ham to me over the counter. I nodded in agreement. "It's just too hard, I go out and instantly," she snapped her fingers, "I want a line like…," she looked around for coworkers, "…this," she measured a good six inches with her fingers and immediately my heart skipped a beat. I wanted to ask her if she had any, if she wanted to go out the next week. I knew she was as full of shit as I was. We try to play it off, to do the right thing, but both of us were sitting with our feet dangling precariously off the edge of addiction, just waiting for someone to make a move. It was why NA could never work for me. I'd gone to a meeting and found myself surveying the room, radar in tune,

looking for the one who was not dedicated to recovery. Which person would be the one willing to beat it on out of there with me and get fucked up? I was never really dedicated to the idea of recovery. My life had not gotten that bad. My addictions had never really taken me to rock bottom. Maybe they never would. Despite having nearly three years of relative sobriety, I found myself occasionally fighting cravings so intense they scared me. I debated on whether I could carry the secret load of addiction and be just fine. I didn't have to be John Candy or Janis Joplin or John Belushi. I could keep being me with that one foot inches above the precipice for a long, long time. I'd dabbled again in my vices before meeting up with Yvette that evening at the grocery store, but somehow through my role as a mother of two, as a wife, as a member of the online CF community, and through my friendship with Don, I had begun to have a new outlook on myself. I found that I felt too bad after a night of feeling good to keep it up. I was proud of the person I had become, was becoming, and I didn't feel such an intense need to try to numb my feelings anymore.

Don was the first person I feel I had ever been truly honest with about my addiction. I admitted to him that in some ways it was a conscious choice to use drugs as proof that I could test my body's limits. Don had done the same thing; it was something we talked about frequently. We discussed the pros and cons of living life in that way. Don had even come up with a mathematical algorithm in which he predicted that living life the way we did probably took about four years of length off of the life time. We decided that the four years was worth it, not to have lived under the blanket of CF all the time. When I did dabble, Don was not judgmental of me, even on th engihts I was so fuicked up Itypedllotlike this and expected himt obeable to read ti. Before meeting Don I

hadn't found anyone who could understand why a person with a debilitating illness would choose to abuse her body even further.

"Did I even tell you I had a memoir under contract about drinking and fucking and doing drugs and having CF?" Don wrote one afternoon. "I did do all those things of course, but the narrative was so bent that it started to become pure bullshit, and after I was in the hospital thirteen times in two years, I realized I didn't have the same cavalier attitude about CF anymore. I think I was 31. I'd gone from living breathlessly to just being S.O.B (short of breath)."

"What's interesting," I wrote in reply, "is that I have always written about addiction and I have always written about CF, though both silently - in journals and on scraps of paper no one ever sees. It is just recently that I've started putting two and two together. I wonder though, how much I am creating a liaison between the two because it makes for a good piece of prose, and where there really is one? I know that I started smoking as a teenager very much as a rebellion against CF, but after that initial "gateway" (haha) what did CF have to do with it? Sometimes I think nothing. I think the choices of friends I made at that time were much more relevant to the addiction, as was a boyfriend who was seedy and shameful and risqué and exciting all rolled into one, with a fierce addiction when I met him (but God, was he beautiful!). I mean, CF was so much not a part of my life during the height of the wild times. So it is a bit, as you say, that I'm running around clinging to my own personal drama. I am certainly hashing things out with my protagonist-self as well. Part of me finds it cathartic; part of me finds it terribly self-indulgent."

Don's reply came quickly, "I was 32 when the 13 hospitalizations started. It was innocuous enough at first. Thirteen trips to the clink start with one, after all. The one is random. The second is a coincidence, etc. But at some point I was vented, and at another I fell into a coma. Still, between stints, and sometimes even during them, I kept up my usual ways. R threw me out finally. I lived in my car, with my dog, thinking that was a great chapter. But eventually sickness, constant, serious sickness, made the memoir a pile of shit and made me realize nearly everything that came out of my mouth was a pile of shit -- the "asthma," the fake trips out of town, etc. Finally a dude took me in as roommate and immediately regretted it. I stole his pot and drank all his Budweisers. He was a douchebag anyway. I opened up Sinister Liquors every morning at 8, avoided my agent's calls, and finally took the pills but got saved. Even when things cleared -- as unpredictably as they'd started -- I kept it up, my baseline remarkably unchanged. It was ultimately untenable of course, not only physically but also spiritually, but I'm inherently led by my weaknesses, my creatureness."

In the literature for Narcotics Anonymous there is an entire section devoted to self-acceptance. Part of the leaflet reads, "Before coming to NA, most of us spent our entire lives in self-rejection. We hated ourselves and tried in every way we could to become someone different. We wanted to be anyone but who we were." One of the biggest concepts that my friendship with Don taught me was that by hating my CF, I was hating myself. I had never put the two together. For me, the disease had always been an entity in and of itself. It was not a part of me, I took no ownership if it. Instead I did all I could to ignore and pretend it did not exist.

Don and I talked about our denial long into the nights. As our friendship forged on after our meeting, I confessed more and more of my fears and truths about who I was to Don. Most of our conversations continued to take place at night when I could be alone to say what I wanted, without my husband or children reading over my shoulder. They didn't understand. No one understood. Only Don understood the secret of CF. Only Don.

Don and I met up again in November of that same year. His health was declining and he had been diagnosed with BOS (bronchiolitis obiterans syndrome), or chronic rejection. He began debating the idea of another transplant. He underwent serious immunosuppressant therapies and grew increasingly more depressed. I started to see sides of him that I didn't know before. He became angry, even mean sometimes. I felt very responsible for him, to be there when he needed a friend. Sometimes I would stay up late into the night chatting with him despite knowing I had to rise early and take care of my children. Most of our conversations were still online, mostly out of respect for George. Don and I always maintained our friendship firmly on the right side of the matrimonial line. George tolerated the friendship well, though I never tried to push the limits. I sometimes felt he was grateful to have someone else to take the burden of my new desire to talk about my disease off him. George knew I now considered Don one of my best and closest friends and that if he needed me, I would be there.

When we met in November, I was in Chicago with my husband and daughter for a Chicago Bears' football game. I left the two of them with cousins I had in town and took the train up to Don's neighborhood north of the city. We met at a restaurant called "The Heartland." I'd bought Don a tiny Ganesha statue when I had been in California earlier

that year, right after he was diagnosed with BOS, and I gave it to him that day. When I'd walked into the restaurant Don had on his oxygen cannula and a scarf wrapped around his neck. His eyes looked sad, unsure. Don removed his cannula while we sat in the restaurant; his portable oxygen tank sat at the foot of the table. The only picture I own of Don is one of him taking a disinfectant wipe to the Ganesha statue; he wanted nothing to do with the possibility of contracting my germs. In the picture his face is puffy from the meds he was on, his hair longer, his demeanor more subdued. He wasn't the happy and vibrant man I'd walked shoulder to shoulder with in July. His upset over the path his health was taking had become palpable.

Not long after our meeting I received an email: *Part of the social contract is that we hide death away, whether it's via hospice or some other means. I'm not exempt. Sorry for what I've already exposed you to.* I replied to him that by no means did I want to be excluded from any part of his life. I was unsure of how to talk to him when he discussed dying, as so often that discussion was accompanied by him explaining his desire to make the call, to choose when and how he was going to go. He maintained that he did not want to die in a hospital. A second transplant was a possibility for him, though he was unsure he wanted to endure it all again. He'd become bitter that the transplant was nothing of the life-saving procedure that it was chalked up to be, but instead just a means of extending one's suffering. Don handled suffering well, heroically even, but my heart ached for him.

When Don talked about his death I always told him that I supported whatever he chose to do, but that I didn't want him to die. I told him many times how important he was to me and that I would be sad if he chose to end his life without looking at all the

possibilities, but I supported whatever it was that he wanted. Retrospectively I wasn't really supporting him, I was afraid of losing him. I never knew if I was saying the right things. I had never been friends with someone dying before.

December 2009

Walking out in the freezing rain, I feel nothing 'cause I numbed the pain

Joan Didion writes in *The Year of Magical Thinking*, "I know why we try to keep the dead alive: we try to keep them alive in order to keep them with us. I also know that if we are to live ourselves there comes a point at which we must relinquish the dead, let them go, keep them dead." These thoughts seem so representative of Don. He truly believed we needed to take the pressure off the dying and let them go, let them be dead. He often remarked about how much pressure the online CF community put on our dying. We wanted them to be heroic, unafraid of death. Their death was representative of our own. In a group of people who are all largely dying at a rate faster than the average person, death was a significant occurrence and large topic of discussion. We all had opinions on how it should be done. Don believed we needed to let the dying be in peace. In a letter he wrote to one of our dying cystic friends he said, *The writer Dostoyevsky, trying to find meaning among the unthinkable hardships in the Russian gulags, decided that suffering was not only an affliction but also an asset, a way to hone our character, our strength, our faith. He said our task was not to avoid suffering but to try to live up to it. We live up to it by not letting it consume our inner selves, by not forking our will over*

to it. I don't say this often, but you have lived up to yours. You have earned the right to let go.

As Don's health declined more, his kidneys began to give out. He refused dialysis. Don never changed his mind on wanting to die in his own way, not tethered to tubes and machines in a hospital. He still spoke often of suicide; he wanted the final say.

"When I die, post on the forums for me, will you?" he asked one night. I agreed.

"But don't write "Breathe Easy," he wrote, "I hate that. How about "Pee Easy?" It's more apropos." I laughed and agreed. Whenever a fellow CFer died, someone inevitably wrote the words "Breathe Easy" on the thread announcing the death.

A few days before Thanksgiving, Don and I chatted in the box. He was not well.

"Do you want me to come up?" I asked. Chicago wasn't far. I didn't know how I could help or what I could do, but I knew that if Don wanted me there, I would go.

"Only if you take LSD with me," was Don's reply. Typical of him to brush off the seriousness of the situation. I laughed aloud and responded, "I will, but you'll have to buy it. I wouldn't know where to go." I wanted to believe that if he was joking, he was OK. I wanted to believe, as I had watched him decline over the past year but yet still hang on, that this was simply another hill he'd have to climb in the life post-transplant.

"Actually, my dying wish is to sleep with you," Don wrote. I gasped, my face flushed on my side of the computer. I was surprised and flattered. Don had always stayed firmly on the appropriate side of the line in our friendship.

"I think taking acid is a better idea," I answered, unsure of the right way to respond. A few days later Don apologized for his off-color comment. I told him not to be sorry, it may have been the most flattering thing anyone had ever said to me. I told

him that I loved him. It seemed very important at that moment that I made sure he firmly knew how I felt.

On December 5th, 2009, a lazy Saturday morning, I logged into my Facebook account as part of my usual morning internet ritual. The first status update I read was from a CF friend. It simply said, "R.I.P. Calidore, Breathe Easy." My vision became blurry, and I felt shock and confusion. It could not be my Don. I scrolled through the posts and saw that the CF community had gone crazy with the news. Don, "Calidore," was dead.

I stared at my computer screen in disbelief. My hands were shaking. "Oh no. No. Oh no," I whispered.

"What's wrong?" My son kept asking, but I could not speak. This was not real. Don could not be dead. I was absolutely crushed. My heart was beating an insistent staccato in my chest. I began speaking aloud to Don, to myself. I ceased to function, I could only sit and stare at my screen, at his username in my Yahoo box. I frantically searched for missed private messages, some sign or note from him to tell me goodbye. But he'd been trying to tell me goodbye for a few weeks. I just hadn't been listening.

I've never been overly religious, but was raised in a very religious home. One of the readings from the bible that is typically read in the Easter Sunday service is about Mary Magdalene visiting Jesus' grave after his death. Oddly, soon after Don's death, I stumbled across that reading of Mary Magdalene weeping at the grave looking for Jesus' body, then looking up and seeing him standing before her, resurrected.

I felt as forlorn that morning as Mary Magdalene must have felt following the death of Jesus. I looked up to Don in much the same way, not in a blasphemous way - he

wasn't my God - but he was, for most of our relationship, a bodiless voice of confidence, reason, and a teacher. I read the parable with a new understanding, a story of a woman who cannot, does not want to admit that the one she loves is gone. Don had changed my entire outlook on my disease by teaching me not to be ashamed of myself, to love every part of who I was, CF included. Because of Don and my new CF friends, I had begun to be proactive in my health care. This meant that I began to do all the therapies I needed to do on a daily basis to keep infections at bay and I no longer waited until I was gasping for breath and coughing until I vomited to seek medical help. I started to understand my disease and bought the necessary medical supplies I needed to keep myself healthy and had even admitted that I needed occasional intravenous antibiotic therapy. I started visiting the doctor with the frequency required by the CF Foundation. I had even begun to tell people that I had CF, something unthought-of until I realized how self-defeating my secret had become. Turning to my own version of faith following Don's death, I understood that this biblical tale wasn't a story of resurrection, but rather a story of grief. A woman so distraught at the death of her love that she imagines seeing him, she tells of his resurrection. She cannot let him be dead. In Joan Didion's book she quotes Freud saying that grief is a way of "clinging to the object through the medium of a hallucinatory wishful psychosis." This is what came to pass for me that Saturday morning I learned of Don's death and the ensuing nights. I thought I felt his presence, I heard his voice in my mind. How badly I wanted to believe he'd come to me in some way. I dreamed his death was a joke, I dreamed I was searching for him but could not find him. I wished to resurrect him, to have him call me from somewhere warm and say it was all a joke. The first days following his death I felt the cold December wind blow and imagined it was his

soul circling past me. But I had to learn to let him be dead. Don was dead. My life was altered, but Don was still dead.

Don's funeral was held a week later in Chicago. I was invited to speak on behalf of the online CF community. "You all were so important to him," his mother explained to me on the telephone. "If wouldn't be right not to acknowledge it."

I left early that crisp Saturday morning in December when it was not fully morning; the moon was still peeking through the soft pink sky, not yet ready to be overshadowed by the sun. I made a "Don Mix" for the drive: some of his songs, some we'd shared a liking for, some that reminded me of him. I headed west. When the Chicago skyline came into view it was Neko Case, "I Wish I was the Moon Tonight."

I was early for the service, so I pulled into a Starbucks and gathered my thoughts. Tears had threatened and spilled the whole drive, and choking down my granola yogurt was no better. I went over what I was going to say. Public speaking was never one of my greatest achievements. I get nervous and tend to talk quickly. Further, crying in front of people is something I like to avoid. There was no way I could not mention that I had CF in my speech and I said aloud to Don over my coffee, "Only you would understand how hard this is going to be."

I entered the church and was immediately greeted by Don's mother. She introduced me to the family and showed me the pictures of Don they had gathered for the ceremony. Don as a baby, Don going to the prom, Don's travels. In some pictures, I barely recognized him, it wasn't the Don I had ever seen; others were certainly the Don I knew. I started to cry. I was so overwhelmed by everything and still in shock. Don had seemed immortal.

The other speakers were two of Don's friends, his brother, and me. The first speaker told a story about picking Don up at the hospital once, the first time he'd even learned his long-time friend had had CF. He described how as he walked up to Don's room he heard a guitar strumming and a deep Johnny Cash-like voice booming out of the door. He said you could judge a person by if they "got" Don or not. I was pleased to be one of those who "got" him. I was the second speaker and I started to cry as soon as I took the podium.

Hi, I'm Shannon, I am a friend of Don's, and like Don, I have CF....

I began my speech through a squeaky voice and trembling lips. I spoke quickly and stumbled over my words. Several people approached me after the service wanting to know more about my friendship with Don or thanking me for speaking on behalf of the CF community. It was the least I could do. After that, I warmed up a bit and found myself talking about CF to an array of different people: Don's colleagues, his students, a college roommate, cousins, his brothers. There was a bit of awkwardness in some of the conversations. What do you say to a CFer at a CFer's funeral? I explained to several people about the "denial" aspect of having a disease such as CF, and many commented on how they didn't know Don had CF for so long. I was proud that through my friendship with Don, I'd come to a place where I felt confident representing his thoughts on the disease even when he was no longer able to.

I thought I would "feel" Don when I got into his apartment for the reception after the funeral, but it was clear to me that the apartment had been considerably emptied already. I knew there was no way Don lived that sparsely. It just didn't have his presence. His mom told us to feel free to take anything we wanted so I took a Flannery O'Connor

book as well as a Thomas Merton one. The Merton had notes in it, and I wanted something with Don's handwriting in it. I also found the Ganesha statue I'd given him a year earlier and slipped it into my pocket.

Toward the end of the night, a friend of Don's named Will brought out his guitar. He began strumming a few chords and before long, the entire room was singing Beatles' songs together. On my left was an old girlfriend of Don's, Karrie; on my right, Don's dad, and his brother, aunts, and cousins across the way. "*Here I stand, head in hand, turn my face to the wall...*" That was the moment that I felt Don; it was the sending off I knew he would want. We sang him away.

I felt closer to Don after that experience than I even did before; I think I fell in love all over when we all sang. I felt all I missed by having CF, by not being able to hang out with Don more, not being able to hug, not meeting at the "right time." Don and I talked about that "other life" we might have had and singing with his family as our send-off to someone we loved made me aware of what might have been. The other life, I became acutely aware, is the one without CF. Don once wrote to me, *I'd like to say hi if you have the chance, but if not, which seems likely, then another time, my second self.* I now knew without a doubt that I would have faith in that other life, that second chance.

Five months later, Don's family arranged a memorial service and interment to take place in Boston. There would be a service at the cemetery where his ashes would be laid to rest, a reception, and then later that night a CD release party. His brothers and other good friends had collaborated and had taken Don's music, most of it recorded on his home computer, and had it professionally remixed with many of his friends playing background instruments and vocals. His brothers and friends would play Don's songs at

a club in Boston and the proceeds would go to the Cystic Dreams Foundation which they were going to start in his name to help CF patients with the costs of transplant and other disease-related expenses.

Fifteen of us from the online CF community flew in from all over the country to be a part of Don's memorial. Cystics flew in from California, Washington, Montana, North Carolina, and Pennsylvania. Most of us knew one another from only the internet. We called one another both by our screen names and our real names. There was a bond in that meeting that I feel will never be reciprocated in my lifetime. Some of us wore oxygen, some had PICC lines; some were post-transplant, some listed. Some wore masks and stood back, some of us hugged one another. All of us were there for the same reason: we all had CF and we all had lost one of our own.

Standing on the steps of one of the buildings on the Boston College campus where the reception following Don's interment took place, we took a group picture. It was probably one of the largest gatherings of CF patients since CF camp had been outlawed by the Foundation for fears of cross-contamination years before. We joked that Don would love to have seen us all together, but would have balked at the germ risks we were taking. For the most part, we didn't care. We had gathered for someone we loved.

When I returned home, I made the decision to post my Boston pictures on Facebook for the world to see. I still hadn't completely come out about my CF to everyone in my life, but I felt I had come too far to keep hiding my disease. I have never been so proud to be a part of something as I have by finding my niche within the CF community.

Don taught me to love myself. He taught me to value all parts of me and to learn from even the things I've found to be the hardest to accept. Through our friendship I learned that abusing my body was just another form of self-hatred and it would do nothing for me but set me back and dampen my spirit.

I haven't magically recovered from addiction, I haven't hit rock bottom and forced my way up. My support group isn't a recovery group, but it is a group of people who are more like me than unlike. I no longer want to distance myself from other CF patients or from myself. I am learning to love me.

Thank you, Calidore, Don. Pee easy, my friend.

Singing You Away:

An Examination of Community and Self-Discovery through Illness Narrative

For most of my life I've had trouble revealing to people that I have the disease Cystic Fibrosis (CF). To any more than family, close friends, or medical staff, I've allowed the disease to remain tucked away inside of me, a secret I've been ashamed and embarrassed to admit. Even to those who knew about the disease, it was often unspoken; I only revealed my medical history if it was pertinent to the situation at hand. I denied that part of myself and hid it from others as well. Despite harboring the secret of my disease, I still often felt I had a story to tell. The hiding of the secret was, in fact, the story. I wanted to write a personal narrative which explained how, with the help of friends I made in the online Cystic Fibrosis community, I was able to release much of the embarrassment I felt surrounding my disease and accept that the illness was not a shameful secret, but rather just another part of who I am, no different from the color of my eyes or status of my belly button. The purpose of this essay is to find a place for my personal narrative, "Singing You Away," within the academic conversation on illness narratives. I used two key terms from Arthur Frank's work: the "cumulative epiphany" (*Rhetoric* 46), which is a narrative form in which the author comes to understand that the illness has always been a part of who he or she is, and the "dyadic body" (*Wounded* 35), a word Frank uses to refer to the shared experience of being bodies, in this case bodies who are afflicted with some kind of illness. I will examine these concepts later and refer to them throughout this essay as a means to examine the development and analysis of my personal narrative from a more theoretical perspective. Using these two concepts, I demonstrate how my narrative describes the development of my identity as a person with

a disease and how, once I was able to accept that part of myself (particularly with the help of my online friends), I was able to use the medium of narrative to reveal my secret and assimilate the disease into my identity.

Midway through graduate school, I tentatively began to use my disease as a platform from which to write. I wasn't always confident in my decision to use my disease as a topic and I often referred to the smaller essays and creative non-fiction pieces I'd written as my "coming out." I believe I felt the same kind of trepidation a teenaged boy might have when faced with telling his father he is homosexual: how will they (those who didn't know) react; will I still be accepted; will the way they interact with me change now that they know my secret? I felt that writing a longer narrative for my thesis project would be the real "closet opener." My narrative would describe how chronic illness can alienate one from "normal" society at large and how that perceived alienation can manifest itself through several forms. I use concepts from several anthropologists throughout this essay to describe how these feelings of alienation and identity fit into my narrative and how each concept played a role in moving toward the self-acceptance I found once I assimilated myself with the disease via acceptance in a community of others with the same illness. This partnership helped to foster a healing of those feelings of loneliness and alienation and aided in the psychological integration of myself with my illness.

Arthur Frank, along with voices such as Anthony Giddens, Joan and Arthur Kleinman, Susan Sontag, and Susan Wendell, ranks as one of the pedagogical leaders of the illness narrative genre. Frank is best known for categorizing different themes within illness narratives: the restitution narrative, the chaos narrative, and the quest narrative.

He writes more on the subject in his article, "The Rhetoric of Self-Change: Illness Experience as Narrative," whereby he further narrows down his study of illness narratives to focus on those solely written in order to make some claim of self-change. Frank describes four basic formats that he feels these types of illness narratives fall into and describes these frameworks as: "what I have always been," "who I might become," "cumulative epiphanies," and "reluctant Phoenixes" (42). Frank describes the "cumulative epiphany" narrative as "...[a] narrative in which authors reflect on living with an illness throughout most of their lives and conclude that whatever they have become has been formed in and through this illness. This epiphany is the recognition that illness has always been the medium of self" (46). Frank's idea of discovering that the illness has "always been the medium of self" was particularly apt in discussing my own narrative because my story centers around that very discovery. I use my narrative to describe how I was changed by my illness simply by coming to recognize that the disease and the self were always one in the same. I came to this discovery primarily through membership in a social group of others afflicted with the same illness. It was when I came to this understanding that I had the "cumulative epiphany," though the actual "epiphany" was a series of events that served as the underlying structure for my entire narrative.

I wanted to avoid both the journey metaphor as well as the battle metaphor when writing a narrative dealing with illness. I felt that these two metaphors, in relation to illness, had almost become cliché. These two concepts have been adapted into our society in a way that has made them almost the sole discourse when discussing illness, disability, and disease. Obituaries are a good example of how widely utilized these

metaphors are in everyday dialogue about illness. People describe their loved ones as "succumbing to a long fight with (cancer, ALS, epilepsy, etc.)," or as "losing a heroic battle with such and such disease which plagued them their whole life." Many illness narratives and blogs about illness often incorporate the way that illness has changed a person, or how the person has developed into the person that he or she is because of having the illness. Blogs about CF have names or annotations describing the blog such as, "My Journey with Cystic Fibrosis," "Breath Quest" and "Blessed with Cystic Fibrosis." Our society has the need to make some sense of illness and disease and the different issues that accompany these states, so thinking of illness as a journey one must take or a battle one must fight can help give some meaning or purpose to life when the body does not cooperate with the values society places on health. I am not positive that I was able to completely avoid these common illness metaphors, perhaps due in part to my own immersion within the popular socially constructed frameworks of illness dialogue. I admit that my narrative is a story about how illness in some ways "changed" me, though it's not the illness that changed my life, it was accepting the illness as a part of myself that did. This is where I see the difference in my illness narrative. My goal was to approach the narrative with a sort of unanswerable question, much like a Zen Koan – in this case perhaps: what is the sound of one lung coughing? That's said somewhat tongue in cheek, but I wanted it to be clear that my narrative was less of a journey or a battle and more the story of an internal search where the answer that would give "meaning" to life with my illness was already quite clear: to reclaim my own story I needed to accept the disease within me. This was where the "cumulative epiphany" fits in. Throughout my narrative, the disease is always present, even when I tried to pretend it was not. I did not

fight against it, nor did I agree to travel along with it. It just was, and in order to fully understand my identity as a whole person, I had to learn that the disease and my self were not two separate identities. I was born with the disease and it shaped my life even in the moments I tried the most to forget it presence. Frank writes in his book *The Wounded Storyteller: Body, Illness, Ethics*, "People telling illness stories do not simply describe their sick bodies; their bodies give their stories their particular shape and direction" (27). In the case of my own narrative, my sick body gave my story shape long before I put it to paper. I needed to actually write the story to come to a true understanding of how my dual selves --Shannon and Shannon with CF--were one person. The interactions I had on the internet with other Cystics was the mode by which I came to this understanding, making my illness narrative a story based on community and specifically the way that the internet allows one's illness narrative to be constantly shared, changed, and updated. Through this medium, my narrative became one not only about the discovery of self, but of communal sharing as well.

After hiding the diseased part of myself from others, and denying the impact of the disease on my life for so many years, I found that my personal character as the author was growing along with the narrative persona I was giving shape to on paper, giving rise to a distinct identity that was my own both within and without the narrative. Imposing narrative structure on these intangible ideas of self-revealed and self-hidden and the incorporation of the two allowed the development of my narrative self and voice to arise and gain momentum. Hilary Clark, in her forward to a collection of essays about narratives and depression, quotes Oliver Sacks saying, "Our narrative is our identity. One can know one's self only within the context of the narrative" (2). Clark then writes

that "narrative is seen as central in the constitution of identity and culture" (2). Once this narrative identity began to emerge in my story, I was able to achieve the meta-cognitive understanding that I needed to have in order not only to determine the structure and framework of the story, but to put the story to paper at all. I needed a sense of omniscience in order to be able to step away from the self whose actions I described in the narrative and to see how that self changed over time and from that, create the story that I wanted to tell. I understood that writing this paper would solidify my identity as a person with Cystic Fibrosis: an incurable, genetic disease.

"Narrative and self are inseparable in that narrative is simultaneously born out of experience and gives shape to experience. Narrative activity provides the tellers with an opportunity to impose order on otherwise disconnected events, and to create continuity between past, present, and imaginary worlds" (19), write anthropologists Elinor Ochs and Lisa Capps in their article, "Narrating the Self." Putting my illness narrative to paper enabled me to examine the way that my personal narrative was developed first by the experiences I created in hiding the diseased part of myself from the world, and then as the story swerved and the narrative course changed, I could examine how I was influenced by my interactions with others afflicted with the same disease. This act of communal sharing was how I actually came to know and understand my self and my identity on a new and deeper level. Writing this project imposed a sense of order on the way my disease was revealed and it became not just a revelation of myself to others, but to me as well. By telling my story, I had to scrutinize myself, my past, and the events that took place in my life very carefully in order to make sense of and give structure to my personal narrative and my identity as a person with a chronic illness. On the one hand, I

was a person whose illness wasn't visible to the naked eye. I looked healthy and in turn was easily able to hide the illness from others. On the other hand, those who did know often had trouble seeing me as different or disabled, as outwardly and for most purposes, my disabilities were minimal. The act of writing this narrative was a means in itself to help me discover myself within my own story.

I set the narrative up in short vignettes that pick out specific moments in my life that I felt could best shape the story. My aim was to show how I was born with this disease, rebelled against the life and medical prognosis that comes with a disease such as Cystic Fibrosis, and finally found some kind of peace with myself and the disease through the interactions I had online with other people who also had CF. These online interactions later play a large role in the way I hope to enter my voice into the genre of illness narrative, showing through my personal narrative the way that the internet changes the overall concept of illness writing. Narratives are now being written in real time, updated and changing daily through blogs and social networks as people update continually and interact with others as the disease is happening to them. Through these networks and friendships my personal narrative was shaped. These relationships helped to form my identity as a self with disease because as I read the continuing and ongoing stories of others with my same disease I could relate to them in a way that was not available to me at any other time in my life, either because I rejected it, or because the cross contamination risks of the disease were too great to take the chance of meeting in any other way than in a virtual reality. The relationships served as a mirror of sorts whereby I could compare my disease and myself to others with the same disease and

examine how others dealt with their illness and disability, constantly comparing and contrasting that to my own reactions.

The shared experience of interacting with others who were also inhabiting genetically mutated bodies was tantamount to my own development of assimilating me with my disease. Through this online community I finally felt less alone and more at ease with my diseased self, and so much of the shape and direction that my story took was drawn directly from my online interactions with others with the same disease. Frank's work in *The Wounded Storyteller* wrestles through making some sense of the relationships between bodies, or selves, to other bodies (selves) within the framework of illness. He describes those who share in the experience of illness or pain as the "dyadic" body. He calls this a "brotherhood" (35), and says that "the dyadic relation is the recognition that even though the other is a body outside of mine[…]this other *has to do with me, as I with it*" (35). He writes:

> Illness presents a particular opening to becoming a dyadic body, because the ill person is immersed in a suffering that is both wholly individual – my pain is mine alone – but also shared: the ill person sees others around her, before and after her, who have gone through the same illness and suffered their own wholly particular pain. She sees others who are pained by her pain. Storytelling is one medium through which the dyadic body both offers its own pain and receives the reassurance that others recognize what afflicts it. Thus storytelling is a privileged medium of the dyadic body. (36)

Frank uses the term "dyadic" to mean the shared and empathetic relationships between other bodies. I've chosen to use Frank's term "dyadic body" to specifically refer to the

online CF community and the shared experience of dealing with Cystic Fibrosis that occurred on the World Wide Web and was a significant part of my personal narrative.

Ochs and Capps also address the idea of community and shared experience in their work: "Narrative also interfaces self and society, constituting a crucial resource for socializing emotions, attitudes and identities, developing interpersonal relationships, and constituting membership in a community." In my writing, the introduction of the online CF community shifts the storyline from the focus on addiction and my self-perception as a monadic body, which Frank describes as "understanding itself as existentially separate and alone" (36), to where I began to find comfort and community within the very group I was trying to avoid: the disease culture. As an active participant within a dyadic body, the second half of the narrative then describes how I tried to work through understanding the part of myself who had denied the disease and lived life in any way possible to prove that the disease was not a determining factor in that life; I had to integrate that old persona with a new one that found comfort, understanding, and recognition within a community of others with the same disease. My narrative took shape as I wrote my life as born into the disease, rebelling against the disease, and then moving through an assimilation of self with the disease.

The summer before I began writing my own narrative, my reading list consisted primarily of memoirs. Two that stood out to me were David Carr's *Night of the Gun* and Kate Holden's *In My Skin*. Carr, a journalist, writes a memoir that looks back on his years of abusing cocaine. He took a journalistic approach to his writing, actually interviewing the people who were present at different junctures in his life. He then incorporated these different points of view into his story. I thought it was a unique take on the memoir

format, and certainly examined the ideas of truth and memory that always arise when one sets out to write a piece based solely on remembering. Kate Holden's book was a memoir of her years working as a heroin-addicted prostitute in Australian brothels. Her story was certainly intriguing based on the lewd voyeurism she allowed by describing primarily her experiences in the brothel, and less the actual addiction that brought her there in the first place. What attracted me the most to Holden's book was that it was written without fear. She laid herself completely open across the pages of her book and it was that honesty that kept me reading. More importantly, in her short bio on the back cover, it was revealed that her narrative had begun as a project in graduate school. I closed her book and laid it across my lap and thought to myself: *I can do that!* I knew I could sort through the mundane events of my life to expose the gritty, raw stuff that I'd enjoyed spying upon in writings such as Carr's and Holden's. I wanted to include those moments in order to really make my story resonate. I knew that my reader would appreciate an honest narrator and that that honesty would be the factor that would keep one reading. What I hadn't expected was just how hard it would be to put my personal truth on paper. At times in writing my narrative I felt embarrassed, ashamed, and quite sad. On several occasions I thought about quitting and instead writing a completely impersonal literary analysis that would leave most parts of me out. Constantly as I wrote I was applying the kind of self-reflexive thinking that constitutes identity: how will this moment change me? What are my feelings? Where is this going? (Maynard, 2006). There was never a dull moment in the creation of both an authorial self and a literary self in the construction of this narrative. What I mean by this is that as the author, I had to make choices about what to put into the narrative, what to take out, and what would best

benefit my writing in a structural way: where to add in suspense, where to try to draw my reader in and evoke emotion, how to create myself on paper? My literary self was this creation. I became, in part, the person I created on paper. This would be the presentation of my self to the world. While this is a created persona, it was important to balance this persona with the person I believe is me. It was easy to get caught up in the writing and then need to go back and reread for truth. Answering the questions that presume narrative self-identity were not always easy; nevertheless, I hammered on, editing out and then adding back in some of the uglier parts of the story. If my story was to be told, I needed to tell it honestly, for myself as much as for the project, and on a larger scale, for any other person suffering through life with a secret the way I had for so long.

In many ways, the CF story is written at birth and for each Cystic there is a commonality of personal narrative - the outcome of CF is inevitably the same: lung transplantation or death and/or both. Death is an inevitable ending for every life; the difference for a person with CF is the expedience in the time line from birth to death and the constant interruption of "normal" life caused by chronic sickness and infections stemming from the disease. What changes this CF narrative from person to person, and what I wanted to use as a stepping stone for character change and development, is the deviation this shared story makes once the disease takes root and the narrative course is determined via the disease. This occurs both socially: how the disease is encountered and reacted to by the social circle of the patient, and by the pathology of the disease: how, when, and what kind of acute illnesses and distresses take place at what point in time in the life of the patient. Where CF takes hold in one child's lungs and that child has a lung

transplant by age 8, another person is not even diagnosed until the late age of 50. Clearly, these two incidents of life with the disease are different, but each of these cases converges in the shared condition of having CF. For many the burden of having the diagnosis of the disease disrupts life long before the actual physical manifestations of the disease take hold. Anthropologist Ronald Maynard undertook a three-year-long ethnographic study of a core group of adult CF patients wherein he hoped to examine the difficulties CF patients have living under the shadow of a disease that shortens their lives. He further describes how this disease and prognostication can alter or create an illness-centered identity within a person (a "monadic body," according to Frank). He also examines how new medical treatments often place the expectation that a longer life at any cost is better than one shortened by disease, even if that shortened life might be the better lived one. In his essay "Controlling Death – Compromising Life," he writes on the idea of "failed prognostication:"

> What if your body reordered your self narrative? What if you were born with a disease and your parents were asked if they would rather leave you at the hospital to die? And if they took you home and you did not die, what if they were subsequently told you would not live to be a teenager? And then no, not to adulthood? What if, as a young adult, you were told you would not live beyond your early thirties? What if your life was a living testimony to failed prognostication, limited knowledge, and the overestimation of risks, a life comingled and often confused with the mortality of similarly diseased individuals? In short, what if, given your disease, you are a biological success? (227)

The idea that life was to be shortened by CF has been a lingering stigma for my entire existence and was a motivating force in my narrative. I wanted to give voice to the deviation my story took as I struggled against this prognostication. I rebelled against the prognosis of CF long before CF made much of an appearance in my life's narrative. I was rebelling against this "failed prognostication" that had shadowed me for years. In this memoir I've presented my drug abuse as the primary mode that gave shape to that rebellion. Certainly substance abuse was not the only way I rebelled against my disease, but it is a serious way, and it is an intriguing way given the dire importance good health has in our society, especially when one has a life-shortening disease. Substance abuse is certainly not an issue of childhood and the fact that I was able to get to a point in life with this disease to be able to abuse narcotics is a rebellion of sorts against the disease and the prognostication of where that disease would take me. I should never have been healthy enough to even think about such a lifestyle. I did, however, and then even lived long enough to be able to look back on that time of life and put it to paper. This narrative itself is still a form of rebellion against the prognostication of medicine and society on the illness itself.

I've likened my experience in revealing my disease to that of someone of alternative sexual identity who might "come out" to his or her friends and family. Robert McRuer in his book, *Crip Theory,* which examines the relationships between queer culture and disease culture, also writes of disclosing disease as a "coming out." Within McRuer's text, he shows the many intersecting lines between these two marginal cultures and what each went through to try to be treated with equal rights and respect in our society. While his book focuses mostly on the social aspects of being a member of a

marginal group, such as queer culture, whose members try to gain equal rights in a society that would prefer they stay locked away in their proverbial closets, the book contains an extremely interesting piece about a man named Bob Flanagan. Flanagan was also a Cystic, and before his death in the mid-nineties, he'd been known in various counterculture circles for his radical and often outrageous performance art. He and his partner Shree displayed much of the S&M lifestyle they'd adopted through live performance art while incorporating Flanagan's' disease into the work as part of the artistic expression; for example, Shree's beating on Bob's body, while outwardly seeming an act of sado-masochism, dually served as percussive chest therapy for his damaged lungs. While Flanagan was more known for extraordinary stunts such as pounding a nail through the top of his penis, he made it clear through his writing and performances that much of his art and lifestyle served as a means to cope with his disease.

In the section of *Crip Theory* entitled "The Return of the Transgressive: Burning Candles for Bob Flanagan," McRuer discusses how Flanagan's art worked as an expose that challenged dominant social values and revealed to the world what it is to be "sick" and what it is to be "alive." McRuer writes, "They [normative society in general] might, in fact, detect that surviving well can paradoxically mean surviving sick" (183). McRuer continues writing that Flanagan "repeatedly drew attention to how his life interrupted the classic disability narratives more generally and the standard narrative of CF in general" (187). Whereas the classic CF narrative would have had Bob Flanagan dead at age eight, he lived until age forty-one and he lived well. Living "well" is a subjective idea, but the basic understanding of this is that Flanagan was not unhappy with his sick body. He

found ways to control and enjoy his life despite his illness. Though his lifestyle was not normative in terms of the dominant social discourse on health and wellness, Flanagan was abnormal in those regards anyway simply by being diseased. Incorporating his chosen BDSM (bondage, dominance, sado-masochism) practices into the conversation alienated him even further from the socially accepted norm. Thus, while Bob Flanagan was sick with CF, his life was still a testament to being alive while being sick. Flanagan is of course playing with the dual meanings of the word "sick" as a means of expressing both his illness and his BDSM lifestyle from the view point of the dominant social discourse. McRuer's writing examines how Flanagan disregarded and surpassed any limitations and expectations put upon him by being diseased using atypical means of both coping with and enjoying life as he knew it. The apex of McRuer's essay comes in Flanagan's own words as he describes an article that was written about him and the practices he and Shree had been living with and incorporating into their art. In his anecdote, Flanagan recounts how an article which described his use of bondage, his CF, his "sickness," and his sexuality was brought to the attention of someone in the offices at the Cystic Fibrosis Foundation. The woman who saw the article, according to Flanagan, ran around the office yelling, "This isn't good for CF! This isn't good for CF! The Foundation depends on cute little kids dying…those posters of kids with big eyes and sad faces saying 'I'm going to die – we need money for research.' And I'm [Flanagan] like the poster child from hell saying, 'Don't give us money because we'll grow up to do things like this!'" (189).

Like Bob Flanagan's art and BDSM practice, my narrative also reveals a non-normative means of coping with Cystic Fibrosis. I adopted a lifestyle that rebelled against

the rules set forth by the dominant discourse as to how those with chronic illness were meant to behave. Maynard touches on the idea of what is the socially accepted norm of health and illness. He writes that "Idealizing the body and wanting to control it go hand in hand" (213). In this neither Bob Flanagan nor I was so different from the greater society. We also attempted to control our bodies – it was the way that we did so that prevented us from being "normal." This deviance from socially accepted behavior was what made it so necessary that I include some of the grittier and uglier parts of that rebellion into my narrative. As McRuer explained and Bob Flanagan embodied, both normative social culture and disease culture set forth certain expectations about how life is to be lived by the healthy and how life is meant to be lived by the ill. In both cases, as explained by Maynard:

> "Health" is a moral discourse that incorporates an emphasis on individualism, hard work, and material reward....anything that threatens our health has both personal as well as social dimensions related to social constructs of what is unhealthy, disabled, or diseased. Consequently, we affirm ourselves and each other through shared images of health that validate conventional understandings of what our physical and social identities should be as productive, able, and self determined beings" (214).

I wanted my narrative to challenge those boundaries. I wanted to show the "real" way that a life can be lived faced with a chronic illness; the way in which I both submitted to the social constructs of health and illness by trying to hide my illness away paradoxically using a completely disdained method of doing so (drug abuse) by both normative and diseased cultures. I wanted my illness narrative to demonstrate how I challenged

expectations of living "well" under the ideas that Maynard presented as the socially accepted discourse on health, and further, that how one treats the body and pushes the limits and boundaries that are set not only by society, but by having an illness such as CF, is a form of control. This was to be an illness narrative that wasn't about being sick, but was about being alive and living in a way that sick people are not socially supposed to live. If we look at Maynard's idea of our shared image of health being able to achieve material reward through the hard work of an able body, it's easy to see how being disabled challenges the socially accepted way of living well while living diseased. As Maynard writes, "To keep one's disease hidden can be a method of control – of one's body and of one's social narrative" (217). My story is about living "sick" and living well. This is a narrative about trying to control the body by pushing it to extremes that the disease dictates it should not be able to meet and at the same time not allowing anyone to know I was sick. My story is not so different from Bob Flanagan's, nor, I learned, is it much different from the myriad of stories I encountered after becoming entrenched within the online disease culture. Living "well" is a statement that might be challenged. As with Bob Flanagan and BDSM, my narrative describes how I abused drugs as a means to rebel against the expectations I felt were set for me by having CF. Still, for a lot of that time I felt that I was living a life that I found to be fulfilling and rewarding, even if much of that was a matter of instant gratification. For both Bob Flanagan, finding comfort within the countercultural BDSM group, and for me, first trying to fit in with the culture of addiction and then with a disease culture, the idea of the dyadic body remains present. We both looked for a group that could share in our pain and in our experiences

within a sick body. No matter how the reader interprets it, I wanted the story to capture the friction between self, disease, and society.

As I explained in my narrative, in 1989, the gene that caused Cystic Fibrosis was located. The life expectancy for a patient with CF at that time was 18 years. That discovery was met with great celebration and the belief that a cure might be found. While the discovery of the gene didn't specifically lead to a cure per se, it gave researchers a start. During the time that I was writing this narrative, a new drug called VX-770 had been introduced to human trials. This medicine would target the faulty CFTR protein in the mutated genes. This would alter the disease at a cellular level and would have the ability to literally "fix" the way the CFTR protein works by transmitting chloride through the cells. Though this medicine will only benefit a small number of CF patients (it targets only one specific mutation, where there are thousands of known mutations), the medical advancement in the research is huge. Hope was once again on the horizon, this time more credibly, as the lab results were astounding. Sweat chloride levels were actually going down in lab studies of patients proving that the gene proteins were working correctly. People who took the drug undeniably felt better and lab results concurred with this. The life expectancy for a CF patient is currently 37.5 years. The success of VX-770 was very exciting news for the CF community. However, for me, a woman in her mid-thirties edging on toward meeting yet another life expectancy, and not one of the people with the gene targeted by VX-770, it didn't mean much. There is a certain fear amongst the older CFers and those with more severe lung damage that some medicine will pop up to "cure" CF, or like VX-770 to very much alter the cellular function and therefore halt the destruction of the disease in its tracks. The problem is that

the fibrosis of the lungs will not be able to be reversed, so the further along the lung damage, the greater the risk that a miracle medicine will halt one's lung function at a place where full activity is impossible but lung transplantation is also not yet an option and so it becomes a Catch-22. Of course one would not have to opt to take the drug, but matters of insurance come into play, what would be paid for and covered and what would not. So much of illness centers around money and insurance and politics, but that is an entire other essay in and of itself. Focusing instead on the idea of constantly living at life expectancy is a matter examined by Daniel Schubert and Margaret Murphy in an article, "The Struggle to Breathe: Living at Life Expectancy with Cystic Fibrosis." They write that "there are no adults portrayed on the homepage of the CFF website. There are only images of smiling children…such imagery can only contribute to the perception that CF remains a childhood disease, making it all the more difficult for others to understand the issues confronting adults with the disease and for those adults with CF to live their lives" (36). Part of my personal vendetta against CF was the way it seemed to thwart my ability to grow up, even though I did keep growing and getting older. The disease seemed to predetermine my existence as an eternal child: I was going to hit puberty later than my peers and thus always look younger than my years; I was going to be tiny and my credibility as an adult would be questioned well into my late twenties; I was going to be a patient of a pediatric clinic well into my thirties; and I was constantly living at the edge of CF life expectancy. All of these things were the precipitating factors in the path I chose as a child and teenager to fight against CF. My narrative explores and explains the inner struggle that manifests when one is constantly told that she will never grow up or

never grow up normal, and that even if she does grow up, she will constantly face being treated as fragile and childlike.

For me, the struggle manifested as addiction, for Bob Flanagan it was BDSM, for others it's obtaining medical or law degrees, or competing in extreme sports: anything that is the polar opposite of what we were told we would be able to do with this disease. This is also part of the shared experience of the disease I wanted my narrative to examine. Despite how we enacted our rebellion, through the camaraderie I found online, I learned I was not alone in my protest against the eternal childhood that accompanies Cystic Fibrosis. From joining my first online site dedicated to Cystic Fibrosis and becoming enmeshed in that culture, I started a blog dedicated to CF; I read the blogs of others. We friended one another on Facebook. We come to one another first and foremost, often before friends, family, or doctors, for our medical needs and questions. The online community has gotten a lifeforce of its own that one without the disease might find hard to understand. I consider my online CF friends, the majority of whom I have never physically met, to be some of my closest friends. They understand me in a way none other can, and these ideas of failed prognostication and eternal childhood are ones that are understood, shared, and commiserated about, but never really need to be explained. It's all part of the story of CF. As Maynard says, "The stories of the ill are medical stories only tangentially, if at all. They are phenomenological accounts of what it means to live with illness...whereas illness narratives provide a way to articulate the social experience of illness and celebrate people as well as the medicine and technology" (39).

One distinction that separates my illness narrative from many other illness narratives is that I weave a secondary narrative genre into the illness story, one dealing with addiction. Though those addictions developed as a means of coping with chronic illness, they took on a life of their own and are a major focal point of the story. Joanne Muzak, an anthropologist whose dissertation "High Lives, Low Lives: Women's Narratives of Drug Addiction" examines addiction, particularly women's addiction, has come to the belief that addiction occurs as a result of personal pain and a reaction to trauma rather than being related to personal weaknesses or physiological reactions to addictive substances. Within her studies she examines the idea of "insidious trauma" as one of the facets leading women toward addiction. In many cases this is rape, molestation, poverty, or some sort of abuse - physical, emotional or sexual - some overarching factor that serves as the catalyst for the woman to step into the world of substance abuse. In the case of my life and this narrative, the illness precedes and indirectly (or perhaps even directly) is the root cause for the experimentation and ensuing abuse of drugs. Muzak's section entitled "Illness as Trauma and the Question of Drug Addiction as Trauma" states that the "third kind of insidious trauma [Maria] Root describes rather vaguely is that which 'may occur together with the experiences of significantly declining health, progressive debilitating illness, or a markedly decreased ability to function independently'" (192). Muzak is using this work to make the claim that addiction is a form of insidious trauma, with addicts suffering from declining health and then using the disease model of addiction. However, for the purpose of this paper, I think the leap can also be made to say that illness itself is an insidious trauma that may predicate addiction. In the case of my story, the addiction did not stem from pain or

discomfort caused by the illness, nor did the addiction escalate the effects of the disease; instead, the traumatic event that led to using addiction as a means of coping was being born with a chronic disease and living under a medical microscope.

Both Muzak and Maynard make use of the social idea of the "outcast" via disease or addiction, calling this persona the "Other." Muzak examines women addicts in the sense of the "Other" in the same way that Maynard describes the disabled or chronically ill person as feeling "other within the discourses of healthy society" (217). In this same way, Muzak speaks of the female addict saying, " Their white, middle class privilege allows them to retain their individuality at the same time as they take in the otherness associated with drug addition" (33). While Muzak's work focuses primarily on the white, middle-class addict, certainly not all female addicts are white and middle class. However, because I fall into that category, her work was quite appropriate when applying her theories to my thesis. I think I have tried to portray this sense of being "Other" as being a feeling of misunderstood loneliness, a pervasive symptom of the illness. Before I ever found a way to fit in amongst others with the disease, I was still relating as an "Other" in that sense of alienation I mentioned previously. So before meeting other Cystics, I instead found camaraderie with those also identified as "Other" within the segmented group of the addict.

Muzak writes that often the addiction narratives that she encountered began with tales of rejection, abuse and many other "self-professed governing sense[s] of alienation and abandonment, and that, as they explain, drugs provide a relief from this pain" (205). While within my narrative I tried to imply that the drug culture was used as a way to rebel, it was a rebellion from the loneliness I felt at being misunderstood and alienated by

my disease. Muzak further examines the ways in which storytelling or "narrative therapy" (27) is a means by which women can heal from their addictions. I don't want to take the analysis of this project into the realm of psychotherapy, but surely with any memoir there is some form of cathartic healing in the writing. This piece was no different and it would be negligent not to at least touch on the fact that storytelling and the delivery of narrative is often a mode of some sort of healing, personal or mutual. This was also one of the reasons I chose to include within the narrative the anecdote about using drugs in my son's hospital room. I struggled greatly with this revelation; it was something I was truly ashamed of. However, as Muzak examines women's narratives of drug addiction, she discusses the correlation between motherhood and addiction wherein motherhood serves as a measure of the "gravity and severity of [the woman's] transgressions as a female addict" (245). In order to really expose the direction that my life choice was taking I had to take the socially revered honor of "motherhood" and show how far I'd fallen in my addictions as to risk this. Even in the discourse of addiction the mother addict is a stigmatized failure. In this way I wanted to create some sort of climactic moment wherein the narrator self must make a change. This was where my study of the crafting of narrative came into play. There might have been other moments I could have used, but I chose the scene in the pediatric hospital because it was one that I felt would elicit the greatest response from my reader. It goes back to my initial desire to write something raw, gritty, and resonating. That moment, the one I was the most ashamed of, was the one I knew I had to keep in the story if I were to give the story the honesty it deserved. It was after this point in the story that I begin the transition into the second half of the narrative where I focus on how my interactions with the online CF

community served to "save" me from that grave and severe place I had been heading toward. The Internet (the dyadic body) was an important tool in my own self-acceptance as I read the snippets of life stories and personal narrative left behind by others on the computer via forums, blogs, and status updates.

Once I found the online world and became active in it, a new sense of self was slowly morphing out of "Other" as addict and into "Other" as diseased. Within my narrative I used the character of Don as the catalyst in this new self-acceptance. This was true to the role he played in my life, but I made sure to structurally center the moment of character change around Don and Don's wisdom. I felt this was factually true and also gave the narrative a sense of structure and purpose. I built the story up to the climactic cocaine in the bathroom scene and then brought it down to the self-acceptance and gain of personal wisdom with the actualization of the self through my interactions with Don and the others online. What I am describing as the "actualization of the self" is what Frank calls a "cumulative epiphany." It is the moment when one realizes that what is (disease) is what has always been (the person and the disease as one being rather than two separate entities). I feel my "cumulative epiphany" was of a series of epiphanies over the course of my friendship with Don that only came to cohesion once I began writing this narrative and giving shape to the identity I was creating within and through the narrative. Though there were other players involved, I needed the narrative to center around one major figure, and I chose Don to be that figure.

To further develop the idea of the communal narrative, or the sharing of the dyadic body, I used actual emails and posts taken from my online interactions with Don. I wanted to use the actual words we shared for two reasons: first because I feel Don was

more succinct and poetic than I am and I didn't feel I could do him justice trying to paraphrase or recreate conversation, and second as a way to represent the collaborative authorship that my narrative took on via the Internet through blogs, forums, private messages, and chat rooms. Had I not become aware through my online experiences that the trials and tribulations I faced as a person with Cystic Fibrosis were very similar to the experiences that my CF peers faced I might not have been able to put this story to paper. It was the confidence that I was not alone in my reaction to the disease and that my story would be welcomed and understood, if only by my "cysters" and "fibros" in the CF community, that I was able to begin writing about life with CF. It was within the dyadic body of the online CF community that much of the early parts of this narrative were born as I read the words of other Cystics via blogs, status updates, or message boards and found that many of their thoughts and experiences with CF were not much different from my own. I was simply putting my ideas to paper and giving them a formal structure rather than allowing them to float about in cyberspace. My story as a CFer still shared many common threads with other Cystics and so though this narrative is my story and mine alone, many parts of it could easily describe the experiences of others in the CF community. The Internet allows for immediate responses to and from a dyadic body and so that sharing led to the discovery that my story was not as glaringly different from other Cystics I encountered. This realization is then what helped enable the "cumulative epiphany" to occur as I personally, and my narrative self, began to realize how the two "selves," Shannon and Cystic Fibrosis, were actually just one person.

Though I'm not sure whether my narrative fits cleanly into one niche within the genre of memoir, I would say it falls mostly within the illness narratives perhaps with

some cross over into the addiction realm. Certainly there are overlapping themes of both within, and I do believe that one was the catalyst for the other. Both themes are used in the memoir to demonstrate the developing sense of self that came to be through the narrative. My hope is that the narrative will explain in an interesting and thought-provoking way what life is like living with a progressive and deadly illness. I wanted to write without needing a metaphor to give meaning to the reason for the illness or how it progressed. Instead, I hope the story is one wherein simply accepting the self as it is the only lesson learned. I wanted the writing to simply show how one person found her way out of the loneliness and pain that was caused by living as an 'Other' by learning to love herself through the aid and friendship of other 'Others.'

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Shannon North
senorth@prodigy.net

Education

2011 MA in English, focus on Creative Writing, Indiana University South Bend

2000 BSE Secondary English Education, ESL endorsement, Indiana University South Bend

Professional Experience

Writing Instructor at Ivy Tech Community College, South Bend, IN (2010-present): taught introductory and technical writing courses for both a general education audience as well as a specialized trade school audience (Plumber's and Pipefitter's Local Union 172 as a part of their Associates' degree and Apprenticeship program). Created syllabi, constructed and graded writing prompts, essays, and exams, met with students regularly

English as a New Language Instructor – South Bend Community School Corporation, South Bend, IN (2001-2006): Taught grades 4-8 in a bilingual immersion classroom. Responsible for creating and implementing most curricculum.

Nominated "Teacher of the Year," 2005 at Navarre Intermediate Center, South Bend, IN

French Teacher - St. Joseph Catholic Grade school, South Bend, IN (1998-1999): taught 1st year French students. Create and executed lesson plans as well as created and gave exams and met with parents.

Mentor Big Brothers/Big Sisters, 1998

Awards, Publications, Creative Endeavors

2011 – working on creating Master's Thesis "Singing You Away" into a full length piece for publication

2009 – poem "Placenta Encapsulated" published by *Literary Mama* (http://www.literarymama.com)

2000 – English Excellence Award for Graduating Seniors, Indiana University South Bend

2000 – 2nd place ICPA Award of Merit for poem "Yardstick Diplomacy" in Indiana University South Bend's *Analecta*

1999 – *Analecta* poems "Yardstick Diplomacy" and "One Perfect Day; My Perfect Life" accepted

1995 – Susan Clemens Memorial award for Creative Writing, Clay High School, South Bend, IN

1993 – *Poet Tree* – poem "Sometimes it Scares Me" accepted